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Learning needs, barriers, differences and study requirements: how students identify as 'disabled' in higher education

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Abstract Higher educational institutions (HEIs) often categorise certain students as 'disabled' in order to support inclusive and equitable study. 'Disabled' students studying in higher education may be asked to 'disclose a disability', request and agree 'reasonable adjustments' that their institution will 'provide' them, and engage with processes such as applying for 'Disabled Students' Allowance'. However, there is little understanding of preferences and comfort with language in this area, and if students do not identify with terms such as 'disabled', this can create barriers to requesting or accessing support. This paper describes a qualitative study to investigate language preferences for common points of communication with the HEI. We held interviews and focus groups with students (n=12) and utilised discourse analysis to investigate the language used and student perceptions of language. We identified three distinct models of language used to discuss study needs relating to a 'disability', each with language norms and specific nomenclature. Furthermore, we found divergence in preferences in language, leading us to argue that differential and inclusive approaches to language use should be explored.

Key words Disability, language, accessibility, student support, higher education

Introduction

In order to support inclusive and equitable study, higher education institutions (HEIs) often identify and categorise students with particular conditions or study needs as 'disabled students' or 'students with disabilities.' This enables them to identify a specific cohort of students to whom they have a legal obligation to offer additional support in terms of 'reasonable adjustments', and it allows them to report on this student population and evaluate university performance (Riddell and Weedon, 2014; Rose, 2006).

Universities also use this terminology to offer students information, guidance and support, and students are required to use it when requesting support or engaging in disability-related administrative processes. For example, in the UK, this terminology is very apparent when applying for government support for study through Disabled Students' Allowances (DSA).

The study reported in this paper arose from a participatory research exercise conducted with the Open University's Disabled Students Group in a previous project. The objective of the exercise was to identify areas that 'disabled' students wished to see researched in order to form a student-driven research agenda. In the exercise, students expressed strong views about the language used to discuss disability-related study needs; some participants were strongly opposed to the term 'disabled', and there were comments that language used in administrative procedures could either put students off seeking disability-related support, or make them uncomfortable doing so. This was particularly concerning because engagement with support mechanisms has been linked with successful outcomes for disabled students in higher education (HEFCE, 2013).

It was decided, therefore, to conduct a study to investigate students' preferences regarding the language the HEI uses to discuss disability. We investigated the following research questions:

1. What language do students use to discuss their 'disability' or condition?

2. What model of language do students prefer the HEI to use when discussing disability in the context of academic study?

Question 1 was addressed through focus groups and interviews. Question 2 was studied at a larger scale via a survey developed using the findings from the focus groups and interviews. This paper focuses on the qualitative data gathered from the focus groups and interviews to answer question 1. The results from the survey addressing question 2 can be found in Lister et al. (2020).

This study was conducted in a large distance learning HEI based in the UK where 19.4% of students disclose a disability on average. The results should therefore be interpreted with reference to the linguistic context of the UK, as there are strong variances in language norms in different international contexts. However, the insights gained through this study suggest challenges to current practices in communication with students. We therefore reflect on both the application of the approach and the findings in our discussion.

The importance of language around disability

Language and terminology choices when discussing disability are a frequent subject of controversy and conflicting opinions. It is argued that beliefs and values about disability are communicated, often unconsciously, through the language used to describe it (Brandt, 2011; Phipps et al., 2002). For example, using a 'medical model' of speech which focuses on an impairment as a deficit, fault, or something needing to be fixed or remedied (Oliver, 1990), or using a 'charity model' which presents disabled people to be objects of pity (Seale, 2013) can have an impact on a person's self-esteem, sense of identity, confidence and power (e.g. Norton, 2013; Riddell and Weedon, 2014; Watson, 2002; Borland and James, 1999), and can be 'deeply dehumanising' (Kenny et al. 2016). Conversely, 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 (Oliver, 1990). However, this model has been said to perpetuate an unrealistic view of disability, and many disabled people still do not feel they identify with it, or may feel obliged to act in a way that doesn't feel natural to them (Shakespeare, 2002).

Issues with language and identity can have notable consequences in a higher education context. Research has suggested a link between different discourses around personal identity and whether students disclosed dyslexia to their HEI and requested support (Evans, 2014). Furthermore, Coughlan and Lister (2018) show that challenges in communication and administrative procedures intended to support students can have a range of negative impacts, including on stress, attainment, and on the student's perceptions of institutions. Agobiani and Scott-Roberts (2015) highlight another challenge, of whether the official labels applied to students are useful to educators in understanding them and to providing appropriate support. They find that labelling students with dyslexia is not a useful way to understand a person's needs, which often relate to other, 'unlabelled' difficulties such as ADHD.

Studies of language preferences around disability suggest that finding a simple model of appropriate language may not be straightforward, and should not be the sole responsibility of experts or institutional staff. At the same time, research in this area is limited, and the major studies have focused on specific disabilities. Kenny et al. (2016) report on a survey of preferences for language to describe autism. This included respondents with autism, their parents,

professionals, family or friends (n=3,470) but did not specifically target students in higher education. This identified conflicting views between professionals and the other groups about preferred language and around whether autism should be described as a disability.

Rosenblum and Erin (1998) conducted a survey on language preferences around visual impairment amongst professionals and university students (n=897). While the survey identified terms that were consistently perceived negatively across these groups, there were significant differences in preferred terms, with 'low vision' and 'legally blind' perceived positively by professionals yet negatively by students.

Both Kenny et al. (2016) and Rosenblum and Erin (1998) therefore suggest 'preference gaps' between professionals and other groups in the population. In the context of education, these gaps may result in differences between the language prescribed for use, and that which students would prefer to be used.

These findings, which focus on specific disabilities, conflict with the common approach in higher education of grouping all disabilities together in communications and administration. In addition, the research instruments used explore perceptions of a set range of identified common language options, but do not focus on the elicitation of the language used or preferred by the population. In this regard, Back et al. (2016) take the contrasting approach of developing a framework of language use in schools based on a content analysis of 22 interviews with students, parents, teachers and administrators. Rather than only identifying preferences or suggesting that one form of language is appropriate in a values-based approach, they argue that contextual and personal variations in language use should be examined empirically. Their analysis identified three broad categories of language: people-first (referring to the person before the disability), disability-implicit (using indirect references to the disability or not stating it specifically), and disability-first (referring to the disability before the person, or only referring to the disability). Within these categories, 14 distinct forms of language could be distinguished to create a framework of language grounded in data.

Although there has been substantial debate of various language models in disability (Brandt, 2011; Phipps et al., 2002; Ryan, 2007), there has been little research that has explored students' own perceptions of the language they are required to engage with. This research seeks to redress this balance through the development of a mixed-methods approach to investigate the language that students feel comfortable using when talking about themselves and their studies. This approach also focuses on gaps between the language students

feel comfortable engaging with, and the language currently used by the institution. The study was prompted by concern at the author's HEI, which serves a large population of 'disabled students', that differences in language can:

- affect how likely a student is to disclose a disability to the institution (Rose, 2006; Evans, 2014)

- require students to identify themselves using terms that they do not feel comfortable with (Riddell and Weedon, 2014; Watson, 2002)

- affect how likely a student is to seek support, arrangements or adjustments that adapt study to their needs (Fuller et al., 2007; Rose, 2006)

- affect students' likelihood of applying for disability support mechanisms (Fuller et al., 2007; Rose, 2006).

While the area of disability offers its own complexities, language issues such as these should be a broader concern for widening participation agendas; for example, Fowle (2018) talks about 'value-laden assumptions' implicit in terms denoting age, such as 'adult learner' or 'mature learner', and the risks associated with treating widening participation students as 'a homogeneous group.' She also recounts concerns from a UK institution about potential impacts on students if they are required to identify with terms such as 'student from a disadvantaged background' or 'widening participation student'.

These problems require not only consideration of the language that institutions use but also the processes through which we construct or decide on this language. Gibson et al. (2016) shows how the labelling of students generates tensions between support for inclusion and the 'othering' of the students as distinct to the rest of the student population. They argue that institutions need to be proactive in their engagement, with the students as key stakeholders in the process, as they are currently often excluded. Our research is an attempt to follow this agenda and engage students in the creation of the language used to describe and engage with them.

Theoretical framework

We adopted critical pedagogy (Freire, 1970) as the theoretical framework for this study, and developed a sequential mixed-methods approach,

employing interviews, focus groups and a follow-up survey (Owen et al., 2016). As a framework, critical pedagogy aims to support, empower and give voice to people who may be disadvantaged, disenfranchised or disempowered, engaging them through education and dialogue and encouraging awakening of their 'critical consciousness' (Freire, 1970). The structure for the interviews and focus groups was designed according to this ideology, encouraging participants in active reflection and critique on language, while the study as a whole aimed to empower their voice and participation in the language used to describe them.

Ethics

A robust ethical approach was vital for this study as there was an element of deception in the methodology. In order to answer research question 1, we needed to capture an authentic example of the language participants used to discuss themselves and others; however, the knowledge that their language was being analysed would likely affect their language use. Therefore, to ensure that participants' language be as natural and authentic as possible, we did not disclose this objective to the participants in advance. Instead we informed them of this in the second half of the interview or focus group, the part in which the language element was more overt.

We adopted the ethical framework proposed by Stutchbury and Fox (2009) and British Educational Research Association (BERA) ethical guidelines to consider ethical implications of the study (BERA, 2018). Stutchbury and Fox's (2009) framework contains four dimensions: ecological (external influences), consequential (benefits/harm), deontological (avoidance of wrong) and relational (establishing trust). We considered potential deontological and relational implications of the deception and were able to justify this, particularly as BERA guidelines (2018) state that participants may be willing to take part in research even though they are unable to be fully informed about the implications of their participation. However, it is vital in these situations that researchers and participants negotiate consent within relationships of mutual trust.

In order to mitigate any deontological or relational implications of deception, participants were informed of the linguistic nature of the study in the second part of the focus group, as this part explicitly required a critique of language. They were also given the option to withdraw their consent at any stage. To fulfil the consequential dimension, we specified the intended impact

of the research in terms of what we wanted to change and how this could benefit the participants. Ethical approval for this approach, and for the study as whole, was granted by the ethics committee in our institution.

Method

The first stage of the study used interviews and focus groups with up to 3 participants. In these, natural examples of language used by students were gathered, and students were asked to critique examples of the HEI's communication to students about disability and study support. This was then followed by a survey to gather students' language preferences at scale, giving them current examples of communications from the HEI and asking them if and how they would like to change the language used in these. The survey also asked participants to rank various terms used to identify disability (drawn from the analysis of the first stage) using a Likert-type scale, and to explain their preferences. More information on the survey methodology and findings can be found in Lister et al. (2020).

This paper reports on the methodology and findings from the first stage of the study, the interviews and focus groups designed to answer research question 1: What language do students use to discuss their 'disability' or condition? In these sessions, we aimed to investigate the language used by students in discussing disability, and to identify their critical reactions to language used by the HEI. Interviews and focus groups were carried out either face-to-face or remotely, through videoconferencing, telephone or email exchanges, according to the participants' preferences. We aimed to have a small-group dynamic wherever possible and to have most sessions consist of focus groups with two or three participants, either online or face-to-face. However, one student preferred a one-to-one phone call and two preferred a one-to-one email interview. Additionally, in one case, two of the participants in a three-person focus group did not attend, meaning this session was conducted as an interview. Therefore, five focus groups and four interviews took place. Participants were recruited from the population of students with declared disabilities, using a stratified random sampling approach (Kothari, 2004).

The interview and focus group sessions had two objectives: firstly, to gather a sample of 'natural' speech to be analysed for language norms adopted by students, and secondly, to gather qualitative data on students' critique of language used in examples of the HEI's communication about disability and

study support. The interviews/focus groups were split into two parts, corresponding to these objectives; the first was a free speaking activity, the second consisted of critiquing an example of the HEI's communication.

The first part of the sessions consisted of free discussion between participants about their learning journeys. Prior to the interview or focus group, participants had been sent a worksheet activity encouraging them to think about their study journey, from their school days through to their time at university. This promoted them to reflect on different aspects of their learning experiences, such as their memories and impressions of areas such as lessons, tutorials, teachers/lecturers, exams, assessment and their peers. Disability or study needs were not explicitly mentioned but one category was named 'Support for your learning.'

In the focus groups, participants were invited to discuss their journeys with the other focus group participants and to look for similarities and differences. This invariably prompted lively free discussion about their learning journeys. In the interviews, participants were simply invited to talk about their learning journey, and discussion was similarly rich and lively. Despite not being explicitly mentioned in the task, disability and study needs were invariably discussed by the students.

The second part of the interviews and focus groups involved participants critiquing an example of the HEI's communication, chosen by students from three options. The options consisted of:

- the disability disclosure question that students answer during registration

- an example of a student 'profile', giving information about their disability and adjustments required

- an example of the 'if you have a disability' section of a module description, giving advice about potential accessibility implications.

Students were encouraged to focus on the language in the communication, but they invariably also critiqued other aspects, such as format, placement and content.

All sessions were recorded and transcribed, and informed consent was sought from all participants.

Findings

Seventeen participants took part in nine focus group/interview sessions. One person withdrew consent for analysis of a session with two participants (meaning both participants' contributions were not analysed), and technical problems resulted in an inaudible recording of a session with three participants. Therefore, seven sessions with twelve participants in total contributed to the analysis.

The transcripts were firstly analysed using thematic analysis to identify the topics discussed by participants, and secondly using discourse analysis to identify differences in language between participants. Transcripts were analysed and coded using NVivo by four members of the research team simultaneously, after establishing inter-coder reliability using a test case.

The thematic analysis revealed seven topics that were frequently discussed by students: own disability, study needs, measures of success, what the institution should do, what the institution should not do, what the student does and what the student should not have to do. These were used as a framework for the discourse analysis.

Discourse analysis revealed variations in language across the topics; these were coded into strands according to the way the participant framed their disability and the interaction they expected from the HEI. These included support, help, management, medical, barriers, equity, and equalisers. Finally, these strands were rationalised into three overarching models:

a) a deficit or medical model, focusing on the disability itself and issues it causes

b) a support model, focusing on 'barriers and obstacles to study' and institutional support

c) an empowerment model, focusing on student 'needs', autonomy and 'independence', with the institution empowering the student.

Some examples of phrases categorised into these three models are provided in Table 1.

Table 1: Categories of language identified from the focus groups

	A: Students perceiving their disability as a medical issue or deficit	B: Students wanting institutional support	C: Students wanting empowerment to develop skills and strategies for success

Expression of own disability	"illness", "condition", "disease"	"have study requirements"	"different", "disadvantaged", "barrier" "obstacles"
Expression of study needs	"'inabilities", "problems"	"particular study requirement", "extra arrangements"	"learning needs", "coping strategies", "tools and resources"
Measures/ success		"success"	"good results" [i.e. grades], "gain confidence"
What the institution should do	"grant [things]", "help", "understand", "communicate"	"proactively support", "offer personalised support", "look after students"	"signpost", "inspire", "encourage"
What the institution should not do	"use blanket terms", "stereotype [illness]", "label", "intrude"	"frustrate", "take away [support]"	"talk down", "presume"
What the student does	"manage", "cope", "survive"	"understand [the system]", "request", "make people aware of what's going on"	"be proactive", "self-manage", "learn", "work hard", "be prepared",
What the student should not have to do	"struggle"	"Be stuck"	"be frustrated", "be embarrassed"

The words that participants used to express these concepts were assigned to these categories in order to create language models derived directly from their discussion. These could then inform the survey design for the second stage of the study, so that the multiple-choice options contained only words and phrases used by participants during this stage of the study, following the method of Owen et al. (2016).

Discussion

This study aimed to answer the research question: What language do students use to discuss their 'disability' or condition? The discourse analysis identified a range of different terminology and perspectives on 'disability', and these were aligned into three overarching models.

Each model is explored in more detail below.

Model A: Students perceiving their disability as a medical issue or deficit

This model aligns with the medical or deficit model of disability (Seale, 2013), with students perceiving their disabilities as deficits, using terms like 'illness', 'condition' or 'disease' to describe them. They referred to their study needs as 'inabilities' or 'problems' and talked about their activity as a student using words such as 'manage' 'cope' and 'survive'.

Students using this model appeared to be advocating for their conditions to be taken more seriously or recognised as disabilities; one person commented, 'this country doesn't recognise Crohn's as a disablement… I have been attacked on a couple of occasions for using a disabled toilet.' Another said, 'I don't know why people get insulted or think "I have not got a disability" when clearly you have a condition that affects you daily. I don't understand that one bit, you might as well just say "I have a disability."'

Many of the students who used medical model language disclosed multiple disabilities. Of the six students using this model, five disclosed multiple conditions. The disabilities disclosed were mental health issues (3 students), fatigue/pain conditions (3), unseen disabilities (3), mobility issues (2), visual impairment (1) and specific learning difficulties (1).

Model B: Students wanting institutional support

This model aligns to some extent with the social model of disability (Oliver, 1990); students positioned their disabilities as 'study requirements' that necessitated 'support' of various types from the institution.

In this model, the responsibility for student success is placed upon the institution to 'proactively support', 'offer personalised support' and 'look after students'; for example, one student wanted proactive support from their tutor, saying 'I would be happy to get a phone call from the tutor every two weeks to say how is the (assignment) going, and then I would have a chance to say generally okay but a problem with this area.'

Another student spoke about reasonable adjustments as support, saying 'I filled in a form to ask for the medication I take to be taken into account with the continuous assessment. I filled one out last year to get a home exam. I have mobility issues and I'm unable to travel, so the OU set up a home

examiner to come to my house to sit the exam with me. I have to say the support from the OU has been exemplary.' This model places the agency, responsibility and power in the hands of the institution, meaning the institution has the potential to 'frustrate' students or 'take away' support.

Of the three students using this model, two disclosed multiple disabilities. They disclosed mental health conditions (2 students), unseen disabilities (1), specific learning difficulties (1) and autism spectrum condition (1).

Model C: Students wanting empowerment, developing skills and strategies for success

In contrast to model B, in this model the responsibility for study success (and the power to achieve this) is seen as belonging to the students themselves. Students saw themselves as 'different' or 'disadvantaged', and perceived that there were 'barriers' and 'obstacles' in the way of study for them. However, they talked about their 'learning needs', 'coping strategies' and the 'tools and resources' available to help them overcome their study 'weaknesses'. These sentiments align with research that suggests the importance of self-determination as a skill set and trait that enables disabled students to succeed (Cobb et al., 2009).

Students talked about how they perceived their role as students. They felt students should 'be proactive', 'self-manage', 'learn', 'work hard' and 'be prepared'. One student said 'It should be about tools and resources, not adjustments. I would love to have a tick list of tools!'

Communication was another theme; one student talked about making proactive contact with their tutors, saying 'I've long since learned it doesn't help to hold things back, you really need to make people aware of what's going on. It's the knowledge of the student that the tutor needs, being proactive and getting in touch, to me that is the main thing.' These students saw measures of success as both extrinsic ('good results') and intrinsic ('gain confidence').

The three students using this model all disclosed only one disability, a specific learning difficulty (3 students).

Conclusion

This paper has presented the first stage of a study that aimed to gain better understanding of students' uses and preferences for language to discuss disability and study needs. Our findings reveal complexity and variety in the way that 'disabled' students perceive themselves, their disability, their study needs and the role of their institution and of themselves as students. In this study, we rationalised this variety into three overarching models:

a) a deficit or medical model, focusing on the disability itself and issues it causes

b) a support model, focusing on 'barriers and obstacles to study' and institutional support

c) an empowerment model, focusing on student 'needs', autonomy and 'independence', with the institution empowering the student.

There were differences in the representation of disability category across the models. Model A was used by more students, and was more widely used across different disability categories; it was also used exclusively by students with fatigue, pain, mobility or visual impairment issues. Students with mental health issues or unseen disabilities used models A or B. Finally, students with specific learning difficulties were represented in all three models, but this was the only disability category represented in Model C. This population was too small for conclusions to be drawn from this, but correlations between disability category and language model were flagged for investigation at scale in the survey stage of the study, reported in Lister et al. (2020).

There were some limitations of this study. Firstly, the study was conducted in a large UK HEI with a sizable population of students disclosing a disability, and findings may vary in other educational contexts. It would be beneficial to replicate the study in a different HEI or study environment. Secondly, all participants had disclosed a disability to the university, as the stratified sampling approach required a disclosed disability to be listed as a demographic. It would be beneficial to identify students who have a disability but have not disclosed it to the institution and replicate the study with them.

We recognise that research at a greater scale is needed, and we address this in the next stage of the study, which uses a survey to gather students' language preferences at scale. This survey presents participants with examples of communications from the HEI and asks participants if they would like to change to wording to align with models A), B) and C). The survey also asked participants to rank various terms used to identify disability (drawn from the

analysis of the first stage) using a Likert-type scale, and to explain their preferences. The findings from this survey are reported in Lister et al. (2020).

Despite these limitations, some conclusions can be drawn. The identification of three distinct language models in this study supports the contention that disabled students are not a homogenous group, that different views on disability and identity are held and are communicated through language use. This suggests that a one-size-fits-all approach to language is not appropriate, and that correlations between different language preferences and demographics such as disability category should be explored. This aligns with the findings of previous studies of specific disabilities outside the educational context (Kenny et al., 2016; Back et al., 2016) and the broader notion that to really widen participation and avoid the tensions of labelling, HE providers should take a more personalised approach and involve students in the development of this (Fowle, 2018; Gibson et al., 2016). As language forms an essential part of the support an institution offers, this leads us to argue that differential, personalised and inclusive approaches to language use should be explored in higher education in an effort to create a more inclusive approach to student support.

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