

## Article

# "Giving the People Who Use the Service a Voice": Student Experiences of University Disability Services

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**Abstract:** Disabled students are systematically disadvantaged compared to their non-disabled peers and Disability Services can provide important access to accommodations and support. Such services are not, however, without issues. The present study investigates student experiences with University Disability Services in order to identify shared barriers to inclusion and recommendations for practice. Individual semi-structured online interviews were conducted with twelve female students. Each student discussed their engagement with Disability Services as an undergraduate or postgraduate student, and each student disclosed a long-term, nonvisible condition. A thematic analysis was used to identify three themes. These were (1) Identity and Legitimacy (Identification as Disabled, Perceived Legitimacy, The Importance of Evidence), (2) Knowledge and Understanding (Knowledge of Specific Conditions, Knowledge of Disability Services, Disability Services Staff Knowledge and Understanding, Peer Knowledge and Understanding), and (3) Independence and Support (Desire for Autonomy, The Importance of Self-Advocacy, Additional Support). The findings highlight shared barriers to support experienced by students with different diagnoses who engage with University Disability Services. A range of recommendations are provided to improve Disability Services provision (e.g., universities are advised to review the language used to advertise Disability Services).

**Keywords:** academia; accommodations; Disability Services; Higher Education; students; university

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## 1. Introduction

In recent years, there has been a greater focus (with regards to research, policy, and practice) on the accessibility of Higher Education. Despite this, disabled students experience significant barriers in their learning and assessment [1,2] and are systematically disadvantaged at each stage of the student journey. For example, records indicate lower academic performance and retention for disabled students compared to their non-disabled peers [3]. Disabled students are, of course, entitled to a range of accommodations and support, typically coordinated through a Centre of Disability Services. The present study investigates student experiences of engagement with Disability Services in order to identify common barriers to support and provide recommendations for practice.

### 1.1. Disability Services and Accommodations

Disability Services provide a range of accommodations and support to students [4]. These accommodations (e.g., extra time in examinations, in-class note takers, notes provided by staff, assistance with studying techniques, differently formatted exams, and adaptive equipment) can have a substantial impact on student outcomes such as satisfaction, performance, and retention [5,6]. Despite the advantages afforded by accommodations, many students do not engage with Disability Services or disclose a disability [6]. A range of barriers to disclosure and engagement may exist. For example, disabled students may be concerned that requesting accommodations could make them 'extravagant', increasing the likelihood of stigma and negative responses from both staff and students [7–10]. Such issues

may be especially prevalent for students with nonvisible disabilities (i.e., those not immediately apparent to others) who could otherwise ‘pass’ as not having a disability [11,12]. Similarly, in their desire to be treated ‘normally’ at university, disabled students may view accommodations as a ‘back-up’ to be used only when essential or after establishing a good rapport with university staff, even if this approach requires greater effort [8,9].

### *1.2. Structural Barriers to Support*

Structural barriers also limit the accessibility of accommodations. For example, there may be a lack of information regarding the specialized services and accommodations available to students [8–10]. The process of requesting accommodations can also be unnecessarily time-consuming and bureaucratic [13]. Even when accommodations are implemented, students face barriers when attempting to utilize them. For example, individual staff members may not engage with the required accommodations. Effective accommodations are, therefore, somewhat dependent on staff commitment. Indeed, many students are able to recall at least one negative experience with a staff member at their university, contributing to a reluctance to utilize accommodations in future [9]. Additionally, while students do tend to report that their accommodations are helpful, some accommodations are ineffective, which can lead to students no longer utilizing them [9,14]. In part, these accessibility issues stem from a medico-legal approach to disability, perceiving disability to be an ‘individual deficit’ or deviation from ‘normality’ rather than a willingness to address the structural and systemic barriers to inclusion through inclusive design [15].

### *1.3. Understanding Student Experiences*

To understand and address the aforementioned barriers to inclusion and accessibility, researchers and practitioners must work with disabled students, listening to their lived experience of university provisions and recommendations for practice [16,17]. It is especially important to understand the experiences of students with nonvisible disabilities who may have additional concerns (e.g., ‘outing’ themselves) and whose presence in Higher Education is increasing [12,18]. Therefore, the present study investigates student experiences of Disability Services, focusing on those with nonvisible conditions. A particular emphasis is placed on the process of requesting and accessing accommodations.

## **2. Materials and Methods**

### *2.1. Participants*

Twelve participants aged 19–25 years ( $M = 22.17$ ,  $SD = 2.04$ ) were recruited via social media. At the time of interview, all participants were undergraduate or postgraduate students enrolled at a British university. University location, institution type (e.g., Russell Group or pre-92 universities), and subject discipline varied. Students (all White women) disclosed a range of nonvisible health conditions (including anxiety, depression, epilepsy, dyslexia, and ulcerated colitis), and each had utilized the Disability Service at their university. We do not provide the medical histories of each participant to protect participant anonymity.

### *2.2. Research Process*

Social media posts were used to advertise an online interview study ‘investigating the experiences of students who have accessed or attempted to access their University Disability Service to receive accommodations’. Students responding to the initial advertisement were sent an information sheet detailing the aim, scope, and form of the present study. Those wishing to participate were asked to complete a consent form, and explicit consent was obtained for the use of direct quotations. Individual semi-structured interviews were then conducted, allowing the researcher to pursue important topics and clarify meanings where appropriate [19]. The interview schedule was designed to prompt respondents to not only report but also reflect on their experiences. Topics covered during the interview included the process of disclosure and accommodations accessed. All interviews were conducted

and recorded via the Zoom platform, with webcams facilitating the rapport between the interviewer and participants. Online interviews also offered practical advantages, e.g., enabling participants to rearrange the interview if they were experiencing a symptom flare.

Reflecting the importance of researcher authenticity [20], all interviews were conducted by the first author (herself an undergraduate student at a British university). The average interview length was fifty-four minutes, ranging from thirty-seven minutes (Participant nine) to one hour and thirty-seven minutes (Participant ten). It is important to note that whilst interviews addressed a sensitive subject area with the potential to produce distress or discomfort that could exacerbate existing conditions [21,22], discussing emotional experiences can be beneficial [23,24]. Indeed, in the present study, participants appeared to find value in discussing their personal experiences. Participants were, however, provided with debriefing information (including sources of support specific to their condition) after the completion of the interview. The study received approval from the University Ethics Committee and was conducted in accordance with the Declaration of Helsinki.

Interviews were transcribed and anonymized prior to analysis. Interview transcripts were then analysed using an inductive thematic analysis [25]. The researchers first read the transcripts several times and recorded initial codes for each transcript. The researchers then discussed the proposed codes, and duplicate or similar codes were combined at this time. Following the establishment of a coding system, the codes were organized into broader themes to establish a thematic framework before the final themes were identified and checked for discrepancies. Leninger's six criteria were consulted (credibility, confirmability, meaning in context, patterning, saturation, and transferability) to evaluate the quality of the research conducted [26]. For example, we recognize that whilst the findings have substantial credibility and confirmability, the themes may not transfer to another context (e.g., a non-academic situation).

### 3. Results and Discussion

The present study explored student experiences of engagement with University Disability Services. Three key themes were identified through the thematic analysis: (1) Identity and Legitimacy, (2) Knowledge and Understanding, and (3) Independence and Support.

#### 3.1. Identity and Legitimacy

The participants discussed the extent to which they identified with the term 'disabled' and the extent to which others perceived their condition to be legitimate. The importance of medical evidence in accessing accommodations and support was also highlighted.

##### 3.1.1. Identification as Disabled

Consistent with previous research [27,28], students were reluctant to identify as 'disabled'. In particular, students did not feel that they were 'disabled enough'. For example, Participant 10 stated *"I didn't, in my eyes, see it as a disability cause it didn't really affect me every single day"* and *"I didn't see myself as someone that would use that service"*. Similarly, Participant 2 commented *"to know that I am sort of given the same name as someone in a wheelchair, almost doesn't feel deserving in a way"*. This issue (and a subsequent reluctance to request accommodations) is especially prevalent amongst students with nonvisible conditions [29], suggesting that greater support is required for this population. For other students, a reluctance to adopt the label 'disabled' reflected self-stigma [30] or a reluctance to identify themselves as 'different' from their non-disabled peers [31]. For example, Participant 3 reported *"I think I just had a lot of like, like I said, internal stigma around it all"*.

##### 3.1.2. Perceived Legitimacy

Disabled people remain stigmatized by their peers and colleagues [32]. Students reported feeling that the legitimacy of their own disability was questioned by others, be that the university services, health services, or even their peers. For example, *"I worry that*

people think I'm lying or exaggerating [the] truth" (Participant 8) and "sometimes [I] feel like people [who] have invisible illnesses feel a bit judged because it doesn't look to be anything wrong" (Participant 12). The findings suggest that, in addition to supporting individual disabled students, universities should engage in a broader awareness campaign that challenges existing assumptions about disability. In particular, campaigns should emphasize the range of conditions (including nonvisible and fluctuating conditions) that constitute a disability. Education may, of course, be most effective when delivered by disabled people [33]. Positive disabled role models (e.g., academics) who openly discuss their own disability (especially if challenging the dominant deficit model of disability) may also be important for reducing the stigma associated with disability.

Three students expressed a level of frustration in not being 'taken seriously' due to their gender. For example, one participant stated "previously like when I was in High School they just thought it was hormones . . . I didn't want to reach out to anyone" and "I really really think I've got ADHD but I, maybe because I'm a girl I don't know, I just can't, because I've been raped, just can't get taken seriously" (Participant 8). Medical gaslighting, whereby disabled people are dismissed, invalidated, or provided with inadequate care [34], is especially common for women and other marginalised groups [35]. Future research should explore the prevalence and impact of medical gaslighting in student populations. Participant concerns relating to perceived legitimacy and identity suggest that universities should consider the marketing and labelling of their Disability Services. For example, students may be more likely to approach a Student Support Centre rather than a Centre for Disability Services if they fear being 'outed' to other students. Institutions revisiting the language used to advertise Disability Services or the placement of these services should, of course, do so through a process of co-creation with the disabled students themselves [36].

### 3.1.3. The Importance of Evidence

Disabled students commented on the need to 'prove' their disability with medical evidence, a practice they largely accepted as inevitable. As described by Participant 4, "it's only taken seriously when you have it written and signed by a Doctor". Of course, the demand for medical evidence also often resulted in a delay or a financial cost to the student. For example, "10 or 15 pounds for a letter saying like [name] has anxiety and I just thought, I'd like, I could've printed like my CAHMS notes and I was like yeah yeah. So I say like 15 pounds I think 15 pounds and then until I got a letter from a GP Uni wouldn't offer me extra time" (Participant 4) and "I were like right that's fine this doctors note is coming, doctors note is coming, thought it would take like a week to come—it took four months" (Participant 8). Reliance on medical evidence and delayed accommodations are not issues specific to Higher Education [37–39]. It is, however, essential that students are able to access support in a timely manner, as accommodations (e.g., additional time in examinations) cannot be applied to a program retrospectively.

Where patients are required to pay for medical evidence (e.g., a letter from a general practitioner), universities should consider reimbursing such costs or (where there is a general practitioner on campus) providing this evidence free of charge. Where standardized testing is common practice (e.g., for dyslexia), but there is a delay in assessment, universities should consider providing in-house assessments to support timely diagnosis. Indeed, one participant recommended an in-house assessment to address this issue, making the point that this is already often provided to assess for dyslexia, "if you're going to screen for like dyslexia well why not equally other things that are like equally as impactful as well" (Participant 3). Of course, for many students, medical evidence may not be readily available (e.g., as students wait for investigation and diagnosis), and the Association on Higher Education and Disability (AHEAD) recommends that students' self-reports and the opinions of Disability Services professionals take precedence over traditional external medical evidence [40].

### 3.2. Knowledge and Understanding

Participants reported limited knowledge of their own health conditions and the Disability Services available to them. In addition, students commented that the knowledge and understanding of Disability Services staff and peers were also inadequate.

#### 3.2.1. Knowledge of Specific Conditions

In the present study, disabled students did not always fully understand their own health condition or the manner in which this could impact their studies. For example, *"I automatically just thought of [dyslexia] as if it's a specific problem with your learning and reading and stuff like that rather than other conditions"* (Participant 6). Students' lack of knowledge about their own condition is consistent with previous research [10] reporting that students often do not know how to describe their disability to others. Some students suggested that their university could adopt a more prominent role in condition-specific education. For example, *"I think it would have been helpful to have had some sessions at Uni that were like probably to just explain like even though you are dyslexic oh you know it's not just about your writing and reading like you might struggle with these other things"* (Participant 3). Other students sought to educate themselves about their condition. For example, Participant 5 discussed researching her own condition in detail, *"I've got loads of books out on dyslexia and sort of had a little flick through them so I'd say the self-help resources were there, but I only knew about them because I went looking for them"* (Participant 5). Self-knowledge and awareness are an important part of self-determination and self-advocacy [41], and knowledge of one's own disability facilitates access to accommodations [42]. Universities should, therefore, provide students with further opportunities to develop knowledge of their own condition and the potential impact of this on their studies.

#### 3.2.2. Knowledge of Disability Services

Other participants were unclear about the nature of Disability Service or the range of accommodations available to them. For example, *"they offered like quite a few things I've never even sort of considered before. Like things that [I] could have on my laptop like apps and stuff"* (Participant 4) and *"I was very surprised at the level of support they could actually offer. . . I thought they were just going to say extra time and that was about it, but it turned out that there was a lot more support available"* (Participant 6). As a consequence, some students sought to educate themselves about the services available. For example, *"when I was looking at applying I got in contact with their disability services just to understand what they could offer"* (Participant 2). The findings are consistent with previous research documenting student misconceptions about Disability Services or the range of accommodations available [8,9,43,44]. Similarly, research indicates important differences in the expectations or preferred approaches of disabled students and Disability Services staff [44]. It is, therefore, essential that disabled students are supported to understand the services available to them [45].

#### 3.2.3. Disability Services Staff Knowledge and Understanding

Issues relating to knowledge and understanding were not limited to disabled students. Participants reported that Disability Services staff displayed a lack of understanding of disability or specific conditions that led to a low quality of service. For example, Participant 5 stated *"I'd just had a student in training or something those few times but it definitely sort of made me avoid the service. . . I don't know what qualifications she had to do the job that she did. No she was, it was rubbish. It just made me stress out more"*. Similarly, Participant 8 commented *"I just don't think they're trained enough in recognizing when a person's having like a complete mental breakdown"*. Previous research has often focused on the attitudes and behaviours of academic staff or student interactions with academics [46]. As Disability Services staff are typically responsible for securing accommodations, greater attention is required to the training of these personnel. A lack of specialist knowledge is consistent with previous research [47,48], and the effective education and training of Disability Services staff is



essential [49], especially as Disability Services advisors may be recruited from a range of disciplines [15].

Greater recognition and regulation of Disability Services (e.g., accreditation) may enhance provision and the status of the sector [50,51]. For universities with a Department of Disability Studies, greater collaboration between Disability Studies Faculty and Disability Services staff is recommended [52]. Issues relating to formal training are exacerbated by a lack of lived experience. For example, *"I don't know if any of the people on that team are dyslexic or have ADHD or anything like that. You can't help someone whose shoes you've never been in"* (Participant 5). As a consequence, Participant 5 proposed creating a student panel to advise Disability Service Staff, stating *"there should be like a student panel- a voluntary student panel. A maximum, I don't know, 5 to 10 students, or you could rotate each month have an open meeting for students who use the service to attend and speak up on their issues what needs changing so that way you staying up to date with what students require um and you are actually giving the people who use the use service a voice"*. Similarly, consultation with disabled staff has previously been identified as inadequate [53]. Therefore, those working in Higher Education who seek to collaborate with disabled students may find the good practice established by the inclusion of experts with experience in healthcare to be beneficial.

#### 3.2.4. Peer Knowledge and Understanding

Other participants commented on the knowledge of their peers. In some cases, this reflected a desire for non-disabled peers to be more knowledgeable. For example, Participant 2 commented *"I would love for people to just ask. I think there is such a- I don't know whether it's a stigma or a, or a worry around wanting to make someone emotional and someone just ask me the straight up questions. . . I would rather educate people"*. Other participants reported that non-disabled students did not understand the purpose or importance of accommodations. For example, *"I've had conversations with my friends and stuff and I've, I've been, I ask for the questions before an interview cause I put dyslexia and then he's like well that's just not fair like this massive advantage like blah blah blah. . . that I think just like other people still don't fully understand"* (Participant 3). Broader education programmes that address such misconceptions are likely to be of value.

### 3.3. Independence and Support

Participants discussed a desire for autonomy at university and the importance of self-advocacy. Despite this desire for independence, additional support (especially in the area of mental health) was often preferable.

#### 3.3.1. Desire for Autonomy

Several students expressed a desire to be more independent at university than they had previously been. For example, Participant 2 stated *"I knew I needed to figure things out myself and I love my parents to bits but I felt like I was in bubble wrap all the time and I wanted to be able to go away and, you know, still be looked after but have the independence of learning how to function on my own"*. In part, this reflected *"a real loss of independence when I was diagnosed"* (Participant 2). This approach is consistent with previous reports documenting disabled students' desire for autonomy as they enter Higher Education [30,54] and the manner in which this may present a barrier to support [55]. The desire to make a 'fresh start' and prove themselves to be capable adults that could successfully live and study alone without accommodations or support was common. As summarized by Participant 4, *"I just thought like, you know it was like a fresh start, and I move into a new place. . . so I just thought like I'll see how things are, I'll get on and just wanted to prove it to myself a little bit"*. For some participants, this had significant consequences. Participant 6 explained *"I was just kind of pushing through it so I was extremely tired all the time and I end up missing quite a lot of Uni but I didn't ask for any help I just carried on and then I was hospitalized"*. In part, this desire to 'prove' their capability may reflect negative stereotypes that suggest disabled people are less competent or capable than their non-disabled peers [56]. It is important that Disability Services staff respect

disabled students' desire for autonomy whilst communicating the benefits of engagement with accommodations.

### 3.3.2. The Importance of Self-Advocacy

Relative independence at university requires students to self-advocate. As summarized by Participant 1, *"obviously being independent is a lot but I felt better doing it on my own than let's say with my parents or with a teacher. I felt that I could really again really advocate for myself"*. However, this could be challenging. For example, *"I don't advocate in myself in the sense, I just like I think it's just tiring if I had to argue with everybody every time they didn't get it, or every time they didn't do something. I would just be tired"* (Participant 3). Indeed, the relative isolation and independence at university could be daunting. As stated by Participant 6 *"it was pretty scary, I was all on my own"*. Disability Services could place a greater emphasis on the development of self-advocacy skills that would allow disabled students to confidently negotiate accommodations, including accommodations in the workplace after graduation [44,57]. Though the present study focused on the experiences of university students, it is important to emphasize that interventions focused on improving self-advocacy may be introduced at an earlier age [58,59], better preparing students for the Higher Education environment.

### 3.3.3. Additional Support

Though several participants expressed a desire to be independent, over time, many required additional support. The need for further mental health support was especially common. For example, *"I just wish there were more, more, like I emailed Uni so many times like I need therapy and stuff and they were like it's just not something that we provide"* (Participant 8). Eight of the twelve participants discussed 'being checked up on' either as something provided or as something they desired. For example, Participant 7 recalled *"the person that was in charge of the disability stuff would offer, like e-mail me to see how I was doing stuff like that. And I just felt like listened to that and that they actually cared"*. This approach could, however, be limited. For example, *"they did the thing where they give you a 10-min phone call to see how you are, check you're not suicidal, and then they're like 'fine you're not so I'll let you go'"* (Participant 10). Participant 9 recalled, *"I mean even just checking in like every couple of weeks so they're seeing or making sure that you're getting on okay. . . I was just kind of kind of left and there was no exceptions or no kind of empathy—absolutely nothing"*. Previous research supports the utility of a 'significant individual' supporting disabled students to find supportive resources in a Higher Education setting [60]. Overall, the student experiences reflected the general reactive rather than proactive approach often taken by Disability Services staff. For example, *"no one ever reached out to me and said do you want help"* (Participant 5). Universities should support regular contact with disabled students where required and consider a more proactive approach to student support.

### 3.4. Limitations and Future Research

The findings are, of course, restricted by their reliance on a relatively small and homogenous sample. The interviews inform our understanding of White British female students accessing Disability Services as an undergraduate or postgraduate student for support with a nonvisible condition. Though eligible to participate, no male, trans, minority ethnic, or visibly disabled students participated. Additional research is required to understand the lived experience of those whose marginalized identities intersect [61,62]. Similarly, Higher Education systems differ cross-culturally, as does the lived experience of disability [63]. In the future, research should consider the extent to which barriers to engagement with University Disability Services are universal. The present study focused on the experiences of undergraduate and postgraduate students who chose to engage with Disability Services. Interviews were not conducted with disabled students who did not seek support. Most disabled students choose not to disclose their condition and do not seek accommodations [6], which may have a significant impact on their academic

performance [9]. Additional research is required to identify the barriers to disclosure and engagement.

#### 4. Conclusions

The current Higher Education environment disadvantages disabled students though Disability Services provide important accommodations and support. In the present study, interviews with disabled students revealed shared experiences and barriers to inclusion across students with different diagnoses. Three themes were identified: (1) Identity and Legitimacy (Identification as Disabled, Perceived Legitimacy, The Importance of Evidence), (2) Knowledge and Understanding (Knowledge of Specific Conditions, Knowledge of Disability Services, Disability Services Staff Knowledge and Understanding, Peer Knowledge and Understanding), and (3) Independence and Support (Desire for Autonomy, The Importance of Self-Advocacy, Additional Support). A range of recommendations are provided to improve Disability Services provision (e.g., in-house assessment, education campaigns, and the development of self-advocacy skills). Future research in this area should expand on this research to include the lived experiences of students with visible conditions, those with additional marginalized identities, and those who decide not to engage with the Disability Services available.

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