

## B2: Self-advocacy

APP PAR Project Cycle 3 2021-2022

### Appendix: Student Survey Questions

1. Background information		
Topic	Self-Advocacy	
Strand	A: Black British perspectives	
	<b>B: Disability/Mental Health perspectives</b>	2
Specific research question	<i>What are the personal and structural barriers to self-advocacy, how do they impact students with mental health conditions, and how can they be mitigated?</i>	
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2. Executive summary
<p>This project seeks to explore undergraduate students' experiences of and barriers to self-advocacy with respect to their educational and mental health needs and recommend effective practices to alleviate any adverse differences that students who must self-advocate experience. Research data was obtained via an online survey, using both open and closed questions to gather both quantitatively and qualitatively relevant information, that was distributed amongst the wider student body, targeting both disabled (i.e., in this case, students with a mental health condition) as well as non-disabled students.</p> <p>The key findings of this study are as follows:</p> <ul style="list-style-type: none"> <li>- The overall confidence of students to self-advocate is relatively low, with the university being generally considered unhelpful in making the endeavour of self-advocacy easier</li> <li>- Consistent praise for services specialising in supporting students, contrasting the mixed feedback for support from academics themselves (i.e. DoSes, college tutors, supervisors)</li> <li>- Applying for adjustments (exams and/or supervisions) is complicated by highly formal processes</li> <li>- Personal barriers to effective self-advocacy are mostly internalised ableism and a lack of energy while structural barriers include long waiting times, difficult bureaucracy to navigate, and being faced with ableist attitudes</li> <li>- Most frequent suggestions for change: provision of templates/how-to guides (some of which already exist which points to a lack of awareness of these resources/information about them being poorly circulated); extensive staff training; increased admin support</li> </ul>

Recommendations based on the findings are as follows: developing a centralised resource hub to facilitate student self-advocacy; self-advocacy training for students (focusing on logistical education and developing emotional skills); check-ins about student experiences of support needs, i.e., student appraisal of DoS/supervisor support.

### 3. Rationale

In identifying awarding gaps for students with mental health conditions, accessing differentiated learning and/or reasonable adjustments is important for any student with different needs, particularly in a high-intensity, high-stress environment. The self-driven informal teaching style for undergraduates at the University of Cambridge burdens the student for accessing differentiated learning and/or reasonable adjustments. Contact with students by academics, not trained educators, further demands a differently abled student to know what differentiation/adjustments they require. For this reason, self-advocacy has become a major component of one's education at the university.

Self-advocacy comes with a 'learning curve' where each student must discover their own means of communicating their needs while navigating the university institutions (college, Disability Resource Centre (DRC), departments, student union, etc). In turn, self-advocacy is an unwritten, untaught aspect of undergraduate learning resulting in a further academic burden to those with mental health (MH) conditions. Self-advocacy results in time costs by figuring out how to advocate, which may in turn lead to MH costs, all of which occurs in a limited time-restricted environment leading to more stress resulting in negatively affected education. The reality of simply asking for "more time" or "a break" for those with mental health conditions is not as commonplace as would be expected for those students, but rather results in a deficit in reaching one's potential. For this reason we sought to understand the barriers in self-advocacy, its effect on the student, and how to further improve existing structures and systems to alleviate these issues.

### 4. Contextual information (literature review)

*What is self-advocacy? Defining a critical term*

Whilst self-advocacy might appear as a relatively self-explanatory concept, it does not have an officially established definition. It is colloquially referred to as the act of "speaking up for yourself" (Mawhinney & McDaid, 1997, p.380) and "having a say" (Anderson & Bigby, 2017, p.110) in the decisions and plans of one's life, but it manifests itself as a far more complex phenomenon, especially with regards to its uses as a practically applicable concept for disability activism and social movements. Based on a blog post by disabled writer Mel Baggs (2019), Smith and Mueller (2022, p.47-48) raise the following questions about the nature of self-advocacy: "What is the point of labelling particular activities or goals as "self-advocacy?" Who defines these behaviors? What does it mean to self-advocate within systems that are fundamentally not built with disability in mind? How can we think about self-advocacy inside of existing power dynamics between disabled and nondisabled people? What might it mean to think of self-advocacy as *disability community advocacy*?" (highlights by original authors). Despite these crucial considerations, a noticeable number of available publications on self-advocacy and disability do not

explicitly outline their operating definitions of self-advocacy, but rather assume the reader's *a priori* understanding of the concept. Given the points raised above, it is not unreasonable to suspect that this could, in some cases, unintentionally impede the purposes of these publications (i.e. communicating a particular argument or research results pertaining to disability self-advocacy convincingly to their audience). Therefore, understanding a person's or group's own definition/perception of self-advocacy is an important first step in any endeavour that seeks to have a lasting, positive impact on the self-advocacy capabilities and opportunities of an individual as well as the self-advocacy mechanisms of any organisation or institution.

### *Self-advocating at university*

Universities in the UK are legally required to avoid any discriminatory practices towards its disabled students under the Equality Act 2010 (replacing/incorporating the Disability Discrimination Act 1995). The definition of such practices goes beyond simply denying someone entry to a degree course due to their disability but can rather be summarised as “not making effort to include someone in the educational process is discrimination as everyone, including people with disabilities, have the right to access premises, events and facilities and equally benefit from all forms of social engagement” (Lukianova & Fell, 2016, p.1). Furthermore, any reasonable adjustments are meant to be anticipatory, i.e., the university is supposed to have any necessary support provisions readily available as well as being in charge of approaching the student (not vice versa) with offers for support, ideally tailored to an individual students' needs based on their condition(s) and their degree programme as Elcock (2014) suggests. However, such anticipatory adjustments (or any adjustments in general) rely on the student disclosing their disability to the university which is, in itself, a fraught undertaking since some students are reluctant to do so due to fear of being treated differently (or, rather, unfavourably) due to the stigma attached to being disabled, or because they did not identify with the label 'disabled' in the first place (Kendall, 2016). The barriers disabled students face range from the practical (e.g., limited building access for wheelchair users, lecture notes/recordings not available in advance or suitable formats) to the interpersonal (e.g. academics unwilling to accommodate students' needs, dismissive and downright ableist comments towards students) (ibid.) and cannot be tackled with a 'one size fits all' approach (Sampson et al., 2022; Tai et al., 2022). Complicating the matter further are the perspective of university staff who try to support students (see, for example, a small-scale study by Kendall, 2018) whilst also raising valid concerns around managing student expectations and the feasibility of supporting a wide range of needs equally and simultaneously.

No matter which particular circumstances a student might face and what their specific support needs might be, the process of advocating for oneself at university can prove to be difficult for many students. Besides the issues surrounding non-disclosure, Bruce and Aylward point out that “disability is usually positioned as ‘an individual “problem to be fixed,” rather than an opportunity to reconceive what inclusion “means” in higher education’ (Cox 2017, 559)” (2021, p.14). They continue: “Bureaucratic borders define who qualifies for support within a medicalized frame that situates disability as deficit or lack (Oliver 2009), and accommodation procedures generally align with mainstream notions of access as an individual undertaking (Titchkosky 2011)” (ibid.), aptly summarising one of the key issue around disability support in Higher Education: the conceptualisation of a disability as a non-normative state of deficiency that the individual carries the full responsibility for. This mode of thinking continues the characterise the dominant understanding of disability in the HE sector and has the potential to

significantly affect the advocacy efforts of students due to an undue amount of pressure and work placed on them to essentially ‘make up’ for their own ‘shortcomings’ in an environment where an empathetic and accommodating mindset towards them and their needs remains the exception rather than the norm.

### *University of Cambridge-specific considerations*

There are two recent sources that provide an in-depth insight into the realities of self-advocating as a disabled student at the University of Cambridge. A paper published by the Student Advice Service (SAS) in 2021 regarding the application process for mitigating circumstances requests states that “the current process is not always in students’ best interests” (Déry, p.3). Summarised, the reasons for this are as follows:

- “Firstly, the requirement that an application be submitted by the College on the student’s behalf reduces student autonomy, which may have a negative effect upon their wellbeing at what is already a difficult time for them.
- Secondly, the current process lacks clarity and accessibility for students, which can sometimes leave them uninformed and uninvolved, potentially leading to poorer outcomes.
- Thirdly, the process relies heavily on Tutor-student interactions being functional, supportive, collaborative, and transparent. Moreover, there is an expectation that Tutors are well informed, will engage students in the process, and will provide all options available to students in a non-directive way, giving students the space to decide for themselves what is in their best interests. But this is not always the case.” (ibid.)

It is especially the latter aspect that the paper identifies as a source of additional self-advocacy work that a disabled student needs to undertake since managing the relationship with their tutor “requires diplomacy, communication and self-advocacy skills, high levels of motivation, time and effort at a time when the student is potentially already feeling very anxious” (p.10). Furthermore, a study investigating the effects of ‘Cambridge Time’ on disabled students (Bernard, 2020) found that “disabled students are being required to advocate for themselves multiple times to different parties which is causing distress and is a persistent time cost” (p.1), drawing on a number of reports on student mental health in Cambridge as well as empirical research conducted specifically with the ‘Cambridge Time’ concept in mind. These two studies alone (alongside the reports quoted in the latter) provide not only a comprehensive picture of the state of student mental health at this university, but also offer a ‘tangible’ backdrop for the present project.

### Reference List

Anderson, S. & Bigby, C., 2017. Self-Advocacy as a Means to Positive Identities for People with Intellectual Disability: ‘We Just Help Them, Be Them Really’. *Journal of Applied Research in Intellectual Disabilities*, 30 (1), pp. 109-120.

Baggs, M., 2019. *The Meaning of Self-Advocacy*. Thinking Person’s Guide to Autism.  
<https://thinkingautismguide.com/2019/02/the-meaning-of-self-advocacy.html> (Last accessed: 8 July 2022).

Bernard, D., 2020. *What is ‘Cambridge Time’ and how does it penalise Disabled Students at the University of Cambridge?*. Cambridge Centre for Teaching and Learning.  
<https://www.cctl.cam.ac.uk/app-par-project/cycle-1/b-time-costs> (Last accessed: 8 July 2022).

Bruce, C. & Aylward, M., 2021. Disability and Self-Advocacy Experiences in University Learning Contexts. *Scandinavian Journal of Disability*

*Research*, 23 (1), pp. 14–26.

Déry, L., 2021. Mitigating Circumstances and Student Autonomy. Student Advice Centre, University of Cambridge.

Elcock, K., 2014. Supporting students with disabilities: Good progress, but must try harder. *British Journal of Nursing*, 23 (13), p. 758.

Kendall, L., 2016. Higher education and disability: Exploring student experiences. *Cogent Education*, 3 (1), pp. 1-12.

Kendall, L., 2018. Supporting students with disabilities within a UK university: Lecturer perspectives. *Innovations in Education and Teaching International*, 55 (6), pp. 694-703.

Lukianova, N. & Fell, E., 2016. Support for students with disabilities in the UK universities. *SHS Web of Conferences*, 28, p. 1-4.

Mawhinney, S. & McDaid, C., 1997. 'Having your say': Self-advocacy and individuals experiencing mental ill-health. *NTResearch*, 2 (5), pp. 380-389.

Sampson, K., Priestley M., Dodd, A.L., Broglia, E., Wykes, T., Robotham, D., Tyrrell, K., Ortega Vega, M., Byrom, N.C., 2022. Key questions: research priorities for student mental health. *BJPsych Open*. May 10;8(3):e90. doi: 10.1192/bjo.2022.61

Smith, I. & Mueller, C., 2022. The Importance of Disability Identity, Self-Advocacy, and Disability Activism. *Inclusive Practices*, 1 (2), pp.47-54.

Tai, J., Mahoney, P., Ajjawi, R., Bearman, M., Dargusch, J., Dracup, M., & Harris, L. 2022. How are examinations inclusive for students with disabilities in higher education? A sociomaterial analysis. *Assessment & Evaluation in Higher Education*. DOI: [10.1080/02602938.2022.2077910](https://doi.org/10.1080/02602938.2022.2077910)

## 5. What do you hope to achieve with this qualitative research project?

We anticipate the outcomes of this project to be as follows: Firstly, to gain a sense of understanding of students' fundamental understanding of self-advocacy and its related processes; secondly, to understand how students interact with currently available support mechanisms; thirdly; to identify any barriers (personal and systemic) that complicate self-advocacy for students at the university; and lastly, to provide recommendations for actionable measures to be taken by the university to make self-advocacy an easier and more efficient undertaking for students with mental health conditions.

## 6. Methods: generation of evidence

To understand self-advocacy for undergraduate students with mental health disorders we decided to utilise qualitative methods. This was so we could better access different experiences that are not quantifiable and target various issues without going too much into the intersectionality of specific mental health conditions. We wanted people's personal experiences to guide our research, through which we establish themes that could be investigated for further research. This allowed us to recognise various barriers regarding self-advocacy. Participants had a wide range of experiences regarding their impact. Most importantly, we could access ideas and opinions for improving structural and personal barriers. We opted for an **online survey developed on Qualtrics** as our research method rather than interviewing a few individuals since we wanted as many participants as possible to voice their experiences and opinions; furthermore, this approach saved us valuable time that we could invest in other areas of the project. Another advantage of utilising a survey is the reduced likelihood of participants being identifiable via their specific experiences as relayed in an in-depth interview which allowed the participants to be more honest in their answers, regardless of identity or disability.

Within the survey, we differentiated between those with a mental health condition, those with a mental health condition and other disabilities and those without a mental health condition. This distinction relates to the institutional structure of accessing resources in the university through the Disability Resource Centre and is the main cross-sectional difference we were interested in. The survey was the same for students with mental health conditions whether or not they had other disabilities but different for those without any suspected or diagnosed condition. The questions for students without mental health conditions asked about their understanding or awareness of self-advocacy in the undergraduate university structure. Survey respondents were contacted via email during March (university Lent Term) via the Disability Resource Centre mailing list and on social media platforms of the Disability Students' Campaign.

In drafting the survey, multiple ethical considerations were taken into account. The co-researchers had the data filtered through the Cambridge Centre for Teaching and Learning (CCTL) regarding any person-identifying elements. However, email addresses were requested in case of threat to personal harm, which were removed by CCTL before the co-researchers used the data. The second consideration was about participant withdrawal of their data. A specific date was decided should a participant want to forgo usage of their survey responses made available to surveyors. All questions were optional (except the one detailed above) and completing the survey was not required. Lastly, concerns regarding the mental health of participants was of top priority, hence participants were signposted to email addresses of CCTL staff along with key mental health provisions within and external to the university at the end of the survey. Students could access this information even if they quit the survey half-way. CCTL staff members discussed students' responses to identify if further actions, e.g., contacting the student, would be required.

## 7. Small project research findings

In keeping with the structure of our survey, the findings will be presented according to the sections of the survey in order to present the results as coherently and accessible as possible (see Appendix for the full list of questions).

76 students responded to the survey. 22 blank responses and 6 incomplete surveys (demographic information only) were removed. Analysis was conducted on a final sample of 54 students.

### Demographic characteristics

- "Do you have a mental health condition"
  - 72% of students reported as being self-diagnosed and currently pursuing/previously pursued an official diagnosis.
- Official declaration/disclosure of mental health condition to the university
  - 44% of the students said that they had officially declared their mental health condition(s) to the university
- Non-mental health related disabilities (e.g., physical impairments)
  - 54% of the students reported as having a non-mental health related disability
- Gender identity

- 54% of the respondents were female, i.e., the findings of the reports primarily showcase the perceptions and experiences of female students along with 22% of male students and 20% of non-binary students.



### Student's awareness, perceptions, and current practices of self-advocacy

To gauge student's current understanding and perceptions of accessing information and support, students reported not feeling confident about advocating for themselves (40%) and preferring someone else to advocate on their behalf (54%). Most students (38%) said that they do not know how and where to find the necessary information needed to advocate for themselves. Student respondents did not think that the university makes it easy to self-advocate (63%) (See Table 1).

Table 1: Students' perceptions of advocating for academic and mental health related needs (n=54).

	Yes, both for academic and mental health needs	Yes, but only for academic needs	Yes, but only for mental health related needs	No	I don't know	Not applicable

If required, I feel confident in advocating for myself.	12	11	2	22	7	-
If required, I prefer someone else to advocate on my behalf.	30	5	3	10	3	1
I know how and where to find the necessary resources and information that I need in order to advocate for myself at Cambridge.	13	5	2	21	13	
There is a member of staff from whom I can get timely and useful advice when advocating for myself.	22	6	4	14	5	1
The University of Cambridge makes self-advocacy easy for students.	3	3	-	35	11	-

The top three activities related to self-advocacy that the student respondents (n=54) had undertaken or were considering undertaking were identified to be:

1. developing a student support document (SSD) with a DRC advisory (76%)
2. exam adjustments (e.g., extra time, location of exam, alternative modes of assessment etc) (70%)
3. supervision related arrangements (e.g., location of supervisions, timing of supervision, due dates of supervision tasks and more) (59%)

Intermission and double-time were considered by 29% and 11% of the respondents, respectively.

In terms of time spent on self-advocacy, students (46%) mostly reported spending less than 30 minutes a week advocating for reasonable adjustments (including and not limited to accessing information, applying for adjustments and speaking to committees and advisors).

When asked who students are likely to go to for academic and/or pastoral matters, students appeared to seek staff support more than student support. For example, 90% of the students said they go to their



DoSes for academic support, and their tutors for pastoral support (78%), however, most students said they have never considered their JCR officers (63%), Cambridge SU officers (73%), and SU campaign committees (e.g., DSC, BME campaign) (71%). The latter could be due to a lack of clarity on the role of these sources of support, or perhaps staff are perceived to have more authority to facilitate changes. Further exploration is required. Along with tutors, students preferred to approach the college nurse/mental health advisory (84%) and their friends (82%) for pastoral support. 70% of students reported seeking academic support from the DRC.

Between supervisors and DoSes, supervisors were most likely to be approached primarily for academic matters (79%), while DoSes were likely to be approached for both academic (90%) and pastoral matters (41%). Conversely, 65% of the students had never considered approaching their department/faculty members of staff, indicating the importance of college-based support, and potentially further exploration on whether there is any perceived need for the role of departments and faculties to provide academic and pastoral support.

#### Applying for exam and supervision adjustments

The next section of the questionnaire investigated the experiences of students with applications for exam and supervision adjustments (applications, in this context, referring to both formal and informal adjustment requests). Most of the respondents (52%) who had previously or were in the process of applying for adjustments for their exam arrangements and/or supervisions reported that those applications had been successful (see tables below), both in the case of applications that were pursued by the students themselves (52%) and in cases where someone else did so for them (51%). However, despite the relatively small number of unsuccessful applications, all of them were applications pursued by students themselves and not by another person on their behalf (10%).

Whilst the current data does not indicate who the people advocating on behalf of the students were, it is reasonable to assume that they were a person in a position of (relative) influence, such as the student's DoS, college tutor, DRC advisor, or undergraduate supervisor. This, in turn, suggests the unfortunate conclusion that an application for adjustments that is pursued by a student themselves is less likely to be approved than an application put forward by someone in a position of (relative) influence. There is a number of possible reasons why this might be the case, including the lack of the respective student's familiarity with the application process and requirements or simply the perception of an application made by a DoS/tutor/supervisor etc as having more 'weight' (i.e., being taken more seriously). Either way, our findings tentatively (due to the small sample size) indicate that whether a student or someone else puts forward an application can skew the likelihood of a successful application outcome. This might be an issue worth further investigation.

Another noteworthy finding was the difference in numbers of students asking someone else to advocate on their behalf between exam adjustments applications and supervision adjustment applications. Whilst the ratio of (successful) student-led vs external support-led applications for exam adjustments is relatively equal (26 to 25), more than double the amount of (successful) student-led applications for supervision adjustments had been made than the amount of external support-led ones (31 to 16). One possible conclusion to be drawn from this is that students are more likely to ask for someone else to advocate for their needs in terms of exams since exams are, overall, more important

than supervisions themselves as their exam outcomes ultimately determine a student's grade. This could be due to the previously discussed (suspected) power imbalance in terms of whose application is more likely to be successful, which is something the students might know intuitively or from experience; since exam results have the greatest impact on a student's degree outcomes, it is unsurprising if they want to ensure that their adjustments will be approved by asking for someone else to put the application forward on their behalf. Another possible explanation for this might be that the application process for exam adjustments is more formal than requesting supervision adjustments; the latter is usually 'just' a matter of communicating with one's DoS and supervisors whereas exam adjustment applications require a thorough application which students are likely to need more help with.

Table 2: Exam adjustment applications.

	Yes, successfully	Yes, unsuccessfully	No
I have previously suggested/advocated/am currently suggesting/advocating for adjustments to my <b>exam arrangements</b> (n=50)	52%	10%	38%
Someone else has suggested/advocated/is currently suggesting/advocating for an application for adjustments to my <b>exam arrangements</b> on my behalf (n=49)	51%	-	49%

Table 3: Supervision adjustment applications (n=51)

	Yes, successfully	Yes, unsuccessfully	No
I have previously asked for/am asking for adjustments to my <b>supervisions</b> (e.g., due dates, location, one-on-one support).	61%	10%	29%
Someone else has previously asked for/is asking for adjustments to my <b>supervisions</b> (e.g., due dates, location, one-on-one support) on my behalf.	31%	2%	67%

Following on from this, the next set of questions was concerned with learning more about the respondents' personal experiences with seeking support and advice for exam and supervision

adjustments. As for exam adjustments, the responses (overwhelmingly from formally diagnosed students) expressed unanimous praise for services that specialise in supporting students, such as the DRC, college nurses, and the Student Advice Service (SAS), frequently describing their support as 'timely', 'clued-in', and 'knowledgeable'.

In contrast, the feedback for college-based support provision (i.e., tutor, DoS, supervisor) was noticeably mixed. Whilst some respondents reported positive experiences with requesting help from their tutor or DoS, several others painted a rather bleak picture. "My tutor and DoS at the time were not answering emails and were dismissive of me in person" said one respondent, highlighting both the lack of understanding some students face as well as a commonly noted lack of (timely) communication from the colleges. Another respondent described how the information they initially received from their tutor proved to be outdated, with university web pages not being much help either due to their inaccessible wording. It should come as no surprise that services and individuals specialising in supporting student well-being outside of the strictly academic realm do so much more efficiently than a college tutor, a DoS, or anyone who is an academic themselves and primarily concerned with a student's academic progression, i.e., having none, if any, formal training in and informed understanding of how to offer pastoral support to students (although exceptions do exist). Some students are fortunate to have a tutor/DoS/supervisor who is well-informed, understanding, and efficient in their efforts to support them and accommodate their needs, however, this is not universally ensured and can differ from individual to individual, as captured plainly in the quote below.

*"I didn't get any advice initially when I got sick. It was only via the student advice service that I eventually started to get help and I only found them via my partner who was worried about me looking for a solution. My tutor and DoS at the time were not answering emails and were dismissive of me in person. I ended up sitting my exams with no adjustments despite being too ill to get out of bed most days because I was not aware there was any other way. Since then I have changed DoS and Tutor and I have a DRC mentor who is very clued in and helpful at suggesting solutions- sometimes to problems that I was aware were solvable. A lot of the information about what to do when things goes wrong is very difficult to access and rely on you having a good DoS or tutor. Even more things are hidden behind the term 'exceptional circumstances' which you are never quite sure if that applies to you! Since I cracked into the system though it has become much easier to navigate although a lot of it still requires a lot of behind closed doors meetings and a reluctance to alter the status quo. I have been told on multiple occasions that 'if I can't hack it I should leave' - luckily that attitude seems to be becoming more rare"*

This quote reflects a worrying, but unsurprising sentiment that still seems to widely dominate the approach to studying at this university, despite recent efforts to change this attitude. All of these aspects taken together create an environment that makes it difficult for students to advocate for their exam-related needs. "It's difficult having to constantly arrange things when I've got lots of other work" explained one respondent, and another one added: "(...) because I have depression and anxiety and at the time of applying I was in a particularly bad patch which made it almost impossible to get out of bed, let alone advocate for myself or phone the doctor for the medical proof required to get an SSD", highlighting the additional burden students with mental health problems face when trying to advocate for their needs.

Despite the positive feedback regarding student support services, the responses suggested some issues with the self-advocacy process that appear deeply ingrained into the bureaucratic structures of the university, beyond the capacities of any one well-informed, supportive individual within a support service. This might be in part due to the DRC – the main point of contact for the respondents – being underfunded and overburdened. One respondent reported that arranging a study skills tutor, who was supposed to help them with advocating for exam adjustments, took over 4 months after the respondent had to contact the DRC several times to follow up on their request, whilst another respondent stated that preparing their SSD *“took absolutely ages, partly because the process seems drawn out”*. A further respondent even admitted: *“I never really got to speak to my DRC advisor because they are so overworked that I felt bad even asking”*. However, it is not only the limited capacities of the DRC that cause problems for students, but the lack of transparency with regards to the processes involved in exam adjustment requests and the amount of negotiation it takes to arrange said adjustments. One respondent *“found process quite complicated with a lot of back and forth between different people”*, echoed by another respondent who stated *“I found that the process was quite long as it involves speaking to multiple different people to try and sort it out; some people are far less understanding about it than others”*.

With regards to support for supervision adjustments, the responses are fairly similar to the questions about exam adjustments. The DRC in particular was positively mentioned, with college-based support provisions garnering mixed opinions again. Whilst several respondents replied that their supervisors had been very accommodating towards their adjustment requests, others had different experiences: *“The level of adjustment supervisors are willing to provide can vary greatly and that can lead to me feeling uncertain about asking for help and not engaging. I think some supervisors need to be more understanding that students (...) have a lot on their plates”*, explained one respondent, whilst another added, *“My DOS was also helpful, advocating on my behalf and granting me extensions. This is only when I personally emailed them”*, highlighting the additional effort for students to ensure their requests are followed up on.

The following reply illustrates this further:

*“I had a note added to my SSD before the start of the year that supervisions should be organised for me in advance of term, struggles doing that last year is why I had to move to double time, almost ended up intermitting. This year, despite this request, I've had to organise all of my supervisions (with 5+ supervisors, from a list of supervisors per topic, many of whom reply and say they have reached their capacity before start of term). My DoS has stepped in occasionally to organise, but for the most part it has been me”*.

One particular issue that arose around supervision adjustment requests was the uncertainty around the appropriate use of tools such as the SSD. One respondent outlined that there is

*“(...) more support needed with determining the exact boundaries between “feasible and appropriate” and not. Some kind of constraint on how and when this accommodation may be used would lend itself better to helping me manage work”*,

with another respondent describing how they were

*“worried about asking for this kind of adjustment too often as I felt they would take me less seriously or get annoyed if my problems were too recurrent. Other occasions if I needed*

*something from a supervisor I would advocate to them myself, which was a lot more stressful and time-consuming and less reliable as sometimes they would not agree to the adjustments that I asked for”.*

Ultimately, regardless of whether students require adjustments for exams or supervisions, the data collected for this section suggests that the current overarching system does not work to the students’ advantage. The situation is probably best summed up by one of the respondents, describing their experience of seeking support for adjustments as *“very stressful (...) if you're in a place of poor mental health it's hard to muster the courage to reach out, articulate and navigate bureaucracy”*.

### **Personal barriers to self-advocacy**

A common theme for personal barriers was that of internalised ableism and motivation, i.e. *“not being a burden”* and *“the effort of fighting for yourself”*.

*“Not wanting to seem like I'm being over-dramatic or attention-seeking or making a fuss out of nothing. This is based on the social stigma that mental health difficulties [sic] hold I think - a fear of being judged wrongly.”*

Many students recognised their own internal struggles with mental health precluded them from seeking support as it is a draining process; as one respondent said: *“Almost impossible to advocate for yourself when you’re an anxious mess who can’t get out of bed”*. After facing the energy barrier, internal prejudices often stopped surveyors from seeking the help and support they required. Such prejudices were voiced as fear of discrimination, not feeling disabled/deserving enough, not wanting to ‘inconvenience’ others, even embarrassment or shame, especially when previous experiences of seeking support was negative. The quote below demonstrates how personal barriers are interlinked with institutional systems.

*“I was involved in a formal complaint process. Throughout this whole process, granted how unsympathetic the college was during my proceedings, I now feel extremely uncomfortable in this environment - there is no one I may turn to who has any ability to directly influence my college who I trust. I am reluctant to reach out for help - especially pastoral help - to the very people who made me feel belittled.”*

Students also pointedly report the impact of racialised systems on self-advocacy.

*“I think there is a race element as [...] I feel like I reflect badly on other people of my race (which is also related to internalised ableism)”*.

*“Internalised notions of it being bad to ask for help. Don't want to be seen by supervisors as weak, especially in racialised environment.”*

Internal voices such as these reflect a larger societal treatment of different abilities, but also demonstrates how the university fails to combat this issue to make its students feel supported.

### **Structural barriers to self-advocacy**

Beyond the ‘energy’ element of mental health, an overwhelming number of barriers are seemingly institutionalised. Respondents regularly identified with the long administrative toll of receiving official

support combined with the lack of adequate communication and adherence to 'best practices.' Outside the university, receiving medical evidence is a time and energy consuming process often done outside the university (Punton, Dodd, & McNeill, 2022)<sup>1</sup>. The wait times of this process can be over years. In addition, financial costs of required evidence limit students' abilities to garner appropriate materials to present to the university.

Once one looks into the university context, the bureaucracy of accessing and receiving appropriate support (with or without medical evidence) is a major problem faced by students. *"The slowness of the system of putting mitigations in Cambridge is very off putting, especially when terms are so short"* amplifies the time cost struggle. The mis-matched time scales of short terms with long holidays, and the external medical facilities, creates a fragmented and discontinuous process for students. In addition, *"the amount of paperwork required, chasing email chains, following website links, is not user-friendly"*. The informal systems in place for students with disabilities lack the necessary clarity to ease the administrative burden. This all means progress can be too slow for receiving support in time for any part of the year. Those with mental health conditions vary widely in required needs but fast-acting and appropriate support within the university time scale is universal.

*"There is often poor communication between different departments/DoS/tutors etc. Few people who had access to my SSD had read it and those who had often seemed not to understand what I was asking of them in terms of adjustments. Even those who are really helpful are very busy and often don't reply to emails or follow up with the support they do offer. This includes my tutor, college welfare [sic] and university counselling [sic]."*

Additionally, frequent ableist interactions create harmful experiences as reported by respondents as it further decreases (the already low) motivation, increases internalised ableism, and destroys confidence in the system. Staff have been described as *"paternalistic"* or *"unempathetic"* resulting in devalued students. Outright rejection or *"hit and miss nature of systems of support"* further results in demotivated students trying to access support. It is *"hard to advocate fr [sic] yourself when you're not listened to"*. The dedicated centre for disabled students is the DRC, where the long replies or unanswered emails leave students without the required support. Paired with the lack of staff education on assisting disabled students, systematic support is missing which makes *"the whole process feel so isolating. Like I am fighting my own battle, being the only one to co-ordinate actual change"*.

*"(...) Encountering dismissive attitudes reduces willingness to self-advocate -e.g. if supervision is in loud place and supervisor does not want to mitigate this (e.g. close window), more reluctant to ask supervisor again, same with permission to record. General sense of others not getting access needs met, habving [sic] to prove their disability to the college repeatedly, discourages self-advocacy for not wanting to encounter the ableism of it all"*

Talking with tutors or DoSes who do not understand the support available or resources to use delay the self-advocacy process. Lack of education in handling students with MH conditions turns students away from Tutors, DoSes, or Departments that are the very people students are told to turn to for advocating: *"If your Dos isn't very helpful, it's hard to know who to ask to signpost you to the right help"*. Cambridge also has a range of roles to navigate through as demonstrated by this quote: *"The division of roles in Cambridge also makes it hard to know the limits of what you can or can't discuss with*

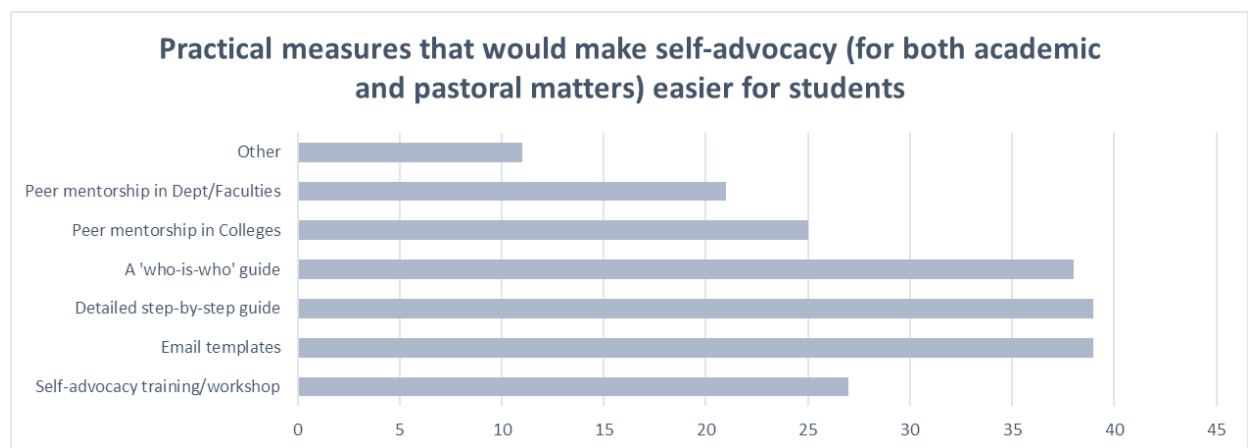
<sup>1</sup> Punton, G., Dodd, A.L. and McNeill, A., 2022. 'You're on the waiting list': An interpretive phenomenological analysis of young adults' experiences of waiting lists within mental health services in the UK. *Plos one*, 17(3), p.e0265542.

*people in certain roles*". Clear, signposted, and accessible resources for students and staff to navigate the different support for students, such as intermission or educational funding, would allow students to adequately self-advocate when academic staff are not educated on the support systems. Discrimination that students with MH conditions face is rampant, most of which can be fixed through adequate staff training/education coupled with stronger educationally (non-academically) focused staff.

*"Social conditioning may make certain demographics of people less liable to either advocate for themselves effectively and firmly if their needs aren't met, or to approach someone to flag up an issue in the first place. Some kind of standardised system to counter these issues would be beneficial, I think."*

### Practical measures to improve the self-advocacy process

As part of our survey, we asked students about possible measures that they would find helpful as part of self-advocacy. A question which suggested various options yielded these results:



What is interesting about these responses is that the two most desired resources, email templates and step-by-step guides to things like intermission already exist, produced by the Disabled Students' Campaign over the years, publicised semi-regularly on social media, and have been updated fairly regularly, i.e., adding email templates regarding remote teaching during the pandemic. This finding speaks to a disconnect in communicating these resources to students with mental health conditions, even those interested and engaged enough to take part in the survey.

In the 'other' category, suggestions by respondents fell into two themes: staff training, and administrative support.

#### Staff Training

In Anna's (student researcher) experience of the APP PAR Cycle 2020-21, staff training around disability is an ever-present request in findings. In this case, supervisors, directors of studies, and tutors were highlighted by multiple students, but suggested different content for these different groups. For supervisors, training around ableist discrimination, and students' legal rights was suggested, to ensure self-advocacy is successful when students embark upon it - as one student reasoned *"If staff don't understand that disabled students deserve accommodations then we shouldn't be expected to convince them"*. For directors of studies and tutors, students wanted training to ensure they are aware of all the

different supports and mitigations available to disabled students and those with extenuating circumstances, so students can easily access information about these options and enable them to guide their self-advocacy.

*“Training for tutors on how they can support disabled students so that they are knowledgeable to answer questions. Training for supervisors and staff more widely on countering their own ableism, so that students are able to confidently self-advocate without being shot down or encountering dismissal”*

### Administrative Support

Students wanted support to reduce the administrative burden of self-advocacy at a variety of levels. This included making it easier to access official support and advocacy tools, such as SSDs and exam adjustments, as well as support for larger scale advocacy, such as complaints against staff, with a clear designated person to help with administration in these cases. Though for the latter, one could argue DRC Advisors and Student Advice Service staff can serve this role depending on context, aforementioned discussion of barriers seems to indicate these current provisions are not satisfactory. One of the authors, speaking anecdotally, notes that though the Student Advice Service can engage in administrative support, students have to self-advocate for this in meetings, as some experiences of SAS can feel similar to being provided additional ‘homework’, rather than alleviating administration.

Students also wanted clear mechanisms to flag a lack of support from designated support structures such as tutors and directors of studies, with one suggesting the need for regular check-ins that reduce the pressure of having to actively make a formal or informal complaint.

*“Maybe if there was a way the senior tutor could put around surveys at the end of term for students to evaluate their dos - because I am worried about contacting and complaining personally and so openly, whereas if it was routine it would feel more accessible to reach help with this”*

One student even suggested that support structures should assume that students with mental health conditions may be struggling, and normalise disclosing this, rather than waiting for students to approach them - *“[The University needs to make it clear] it’s okay to ask for help and even presume we’re struggling because we are, things are so intense but it’s normalised and that needs to change”*.

### Self-Advocacy Training

Another question was aimed at asking respondents what they would find helpful in theoretical self-advocacy training, in contrast to what they may have wanted in previous questions regarding written resources and mentoring.

Multiple students echoed a sentiment that training needed to explain why self-advocacy is not a “waste of time”, and why it is worthwhile, which is emblematic of the current situation with regards to self-advocacy: current barriers have left a perception that self-advocacy is ineffective, and such perceptions need to be combatted alongside the barriers that produced this perception.

Two themes emerged in suggestions - logistical education and developing emotional skills.



- Logistical education covers practical details that may also be covered in the aforementioned written resources, such as support providers and support options at Cambridge, legal rights and reporting/complaining when these are breached, how to follow-up when self-advocacy attempts go unanswered or are rejected. Respondents also suggested it would be valuable to learn how to spot when it would be useful to self-advocate, and how to figure out when a specific support option is the right option - the latter was expanded on in reference to a respondent's experience of wanting to intermit but doubting their eligibility and willingness of staff to support them.

*"How to detect when self-advocacy would be useful; how to navigate the Cambridge system; knowing who to keep in contact with; benefits of advocating"*

- Developing emotional skills around self-advocacy focuses on managing emotions, and emotional labour/energy during self-advocacy, as well as being assertive during the process. One respondent wanted to cover the balancing act of showing the impact of a lack of accommodations without losing their assertiveness: *"[Training should cover] how to ensure you don't allow your needs to be swept to the side or diminished and be honest about what is affecting you without becoming overly emotional to the point where your point [is] lost"*. Respondents also wished for guidance on addressing internalised barriers to self-advocacy, and negative emotions around their disability or asking for support, said feelings were referenced as: *"shame", "feeling like a failure or being a burden", "imposter syndrome and internalised ableism", "I don't deserve help", and "anxiety"*. As such, one respondent also referenced wanting to learn how to talk about disability and mental health with friends and staff. Another also indicated it would be valuable for training to inform students of the value of peer and community support during self-advocacy.

Respondents were also concerned with the accessibility of any resources or training developed, with one noting the value of written resources alongside training, and another noting that the University Counselling Service's assertiveness training was inaccessible to them as it was online-only.

The final question of the survey offered the participants the opportunity to reflect on their understanding of self-advocacy as a concept following the survey as well as any further thoughts on the self-advocacy process for students with mental health issues at the university. The majority of respondents (all of them officially diagnosed students) chose to offer some general thoughts of self-advocacy in Cambridge instead of their understanding of the concept itself, though one respondent in particular offered a valuable perspective on the term:

*"Self-advocacy is maybe a limited conception of how disabled students navigate Cambridge. Without being a JCR officer or anything like that, I am frequently supporting other disabled students who are trying to/struggling to get their access needs met. Community advocacy and peer support is what is happening, as well as self-advocacy"*

In order to create an environment that is as efficient as possible in producing successful outcomes for student adjustment and support requests, any efforts towards strengthening the self-advocacy capacities of students should ideally be matched by boosting material investments towards community

advocacy and peer support. This is, however, not to say that the university should be released from any responsibility to cater to its students' needs – quite the opposite.

The responses to this final question suggest an overall fairly bleak picture of the current circumstances for mentally ill students trying to advocate for themselves. What follows is a small selection of responses that illustrate this situation:

*“It’s such a huge burden that is not appreciated. Ideally we shouldn’t have to be so awfully treated that we have to fight for everything. Our needs should be respected from the outset”*

*“The environment has to explicate its okay to ask for help and even presume were struggling because we are, things are so intense but it’s normalised and that needs to change”*

*“The institution constantly assumes an abled student and consistently makes disabled students jump through hoops or wait for long periods to access necessary support. The message is: Cambridge isn’t meant for disabled students. Self-advocacy is a lifeline, but the individual cannot make up for institutional barriers to full disabled access”*

*“Self advocacy takes a lot of energy on top of trying to do the degree and dealing with the issue itself”*

*“Generally that it’s really hard and long and it makes you feel like you’re designed to fail”*

*“Self-advocacy at Cambridge feels quite nebulous; because the workload can be very difficult and everyone struggles, it can be hard to distinguish between normal struggle and when additional support is needed”*

## **8. Outcomes of research/implications for Cambridge practices and processes.**

The quantitative data surrounding this project suggests that advocacy activities are mostly revolved around developing an SSD with a DRC advisory and seeking exam adjustments. Procedural issues related to these raised in this report have implications regarding the barriers to self-advocacy and how they can negatively impact students with mental health conditions, which may potentially affect the awarding gap.

The qualitative strand of the project articulates the nuances to barriers to self-advocacy, and how these can be improved. The feedback on adjustments for exams and supervisions revealed that the quality of support students receive from non-specialised sources (i.e., their DoS, supervisors, college tutors) can differ vastly from person to person, whereas specialised student support services, especially the Disability Resource Centre, were generally reviewed favourably, indicating that a certain level of training in and understanding of the Cambridge University mental health support system as well as a general appreciation of what students with mental health problems go through on a daily basis is crucial for anyone aiming to provide sufficient support.

Respondents also indicated how they believe these barriers could be reduced, with strong interest in written resources such as email templates, step-by-step guides, who's who contact resources, as well as the logistical education and emotional skills they would hope to gain from any potential self-advocacy training. Overall, the responses painted a rather bleak picture of the current situation regarding self-advocacy. *"Do better please - the lack of adequate mental health support has resulted in a student death at my college already"* one respondent pleaded, highlighting just how dangerous a lack of adequate mental health support for the student body can potentially be, especially in light of several student suicides in recent months:

<https://www.cambridgesu.co.uk/news/article/cambridgesu/Our-Response-to-Recent-Student-Deaths/>

## 9. RECOMMENDED ACTION/FUTURE DIRECTION

Our recommendations are informed not only by our findings with regards to the barriers to self-advocacy revealed in the survey, but are also synthesised from the recommendations of survey respondents, as outlined above.

1. Developing a centralised resource hub to facilitate student self-advocacy
  - This would involve the collation of pre-existing resources, i.e., the Cambridge SU Disabled Students' Campaign's email templates and Intermission and Double Time Guides, and the creation of new resources i.e., a Who's Who Contact Guide
  - To ensure these resources are used, information must be accessible and easy-to-read, and the hub itself must be well-publicised and easy to access
  - Although this is aimed to address the awarding gap for students with mental health conditions, these resources will help all disabled students, and any who encounter mitigating circumstances in the course of their degree, and should be advertised as such, i.e., pointed to as a first step in the same way tutors and directors of studies are.
2. Self-Advocacy Training for students
  - This should cover both the logistical education and emotional skills outlined in the earlier findings.
  - Should be advertised to all incoming students, and to any student who registers with the DRC at any point in their time at Cambridge.
  - Ensure that non-specialised members of staff (DoSes, tutors, supervisors) are also aware of these courses and how to best support students advocating for both academic and pastoral matters.
3. Check-ins about student experiences of support needs, i.e., student appraisal of DoS/supervisor support
  - These should be designed in such a way that students are aware of the actionable benefits of providing these assessments, as some Colleges/Departments ask such questions as part of anonymous surveys where students may be unaware if comments about lack of support are acted upon, especially if they see no change in their experience.

- Stronger communication linkages between Colleges and Departments/Faculties to address the time-costs and procedural burden related to SSDs and overall support for students.

Any of the above recommendations should be developed alongside further student consultation, especially with regards to the development of resources or training outlined in the first and second recommendations, to ensure they are readable and easy for students to navigate.

### [Appendix: Student Survey Questions](#)