

CUSU Disabled Students' Campaign
Healthcare & Services Survey 2018
Report

Disabled Student's Officer Florence Oulds

Introduction

This survey was created in order to obtain concrete data about the experiences of disabled students at Cambridge University, and principally how they use services available to them both inside the University and outside of it.

We also wanted to know their opinions about the quality of these services and areas of support that they were lacking in order to inform our work with these services. In a University where funding is applied for yearly and awarded based on how a department or service portrays its own needs, it's important to be able to supply evidence beyond anecdote of how they can improve so that that change can be made.

The survey opened on Monday 9th April, and closed on June 14th to a total of 47 responses. The survey was open to all self-defining disabled students at Cambridge, and those with any experience of disability or using related services, such as the University Counselling Service or the Disability Resource Centre.

The Disabled Students' Campaign operates on a model of self-identification where we allow individuals themselves to decide if they are disabled or not, rather than basing who is allowed to interact with the campaign on diagnosis. This allows individuals to explore their disabled identity and what it means to them, as well as considering how that relates to the medicalised notion of disability¹.

The survey's 102 questions were divided up into sections relating to specific named services as well as more general areas of provision, such as the pastoral support is available to individuals in their colleges. In this report I'll give a general overview of the answers given, expand on them, and suggest how potential problems may be solved, with a final section highlighting the main issues raised by the survey.

Individuals filling out the survey were informed that their data would be used for this public report, but also sent to specific relevant services, and that their data would be anonymised and not used if it could identify the individuals. We

¹ <https://www.cusu.co.uk/articles/do-disabled-people-need-medical-validation>

hope that the survey will be repeated yearly, and the data used to compare results and find trends in student experience, alongside the data from the CUSU Big Cambridge Survey.

This report is intended for use by students and staff at the University of Cambridge and its related services, other practitioners in Cambridge, disabled people's organisations, and other disabled student groups.

For more information about the report or campaign, or to inquire further about results of this survey, please email the Disabled Students' Officer at disabled@gmail.com

Find the Disabled Students' Campaign online at:

<http://www.disabled.cusu.cam.ac.uk/>

<https://www.facebook.com/cusudisabled>

https://twitter.com/CUSU_Disabled

Contents

5 – Demographics

7 – General Questions

9 – Disability Resource Centre

11 – University Counselling Service

14 – Students' Unions' Advice Service

15 – Pastoral Services

17 – GP Surgeries

17 – Miscellaneous Questions

18 – Findings

Demographics

We collected demographic data to try and make sure our data was representative of the wider University population, and also to find out which groups were engaging with our campaign and which weren't.

Our "average" respondent was an 18-21 year old white British home student, who is a cis woman and either bisexual or heterosexual, a full time 1st year undergraduate, and self-identifies as disabled most commonly because of mental health difficulties which knew about before they started University.

This portrait largely reflects the individuals who frequently interact with the DSC and attend its events and open meetings, but it's also important to acknowledge the variety of respondents we received and that it's statistically unlikely that most of our respondents would fit this "average" profile. For example, while most students who filled out the survey were first years, there were only 2 less respondents who were 3rd years, and 3 less who were 2nd years.

Among the types of disabilities students self-identified as having, after mental health issues the most common were chronic pain/chronic illness, autistic spectrum disorder/ Asperger's syndrome, and specific learning disorders. ASD and SpLDs are both well served in university/educational settings by simple individual adjustments, such as extra time and the provision of assistive technology.

However, the high rates of chronic pain/chronic illness among students is something that should be noted, especially due to the minimal adjustments offered for it by the University and long waiting lists for treatments on the NHS. "Chronic illness" is a broad term often used to describe genetic conditions—such as POTs, Ehlers-Danlos syndrome, and chronic fatigue syndrome—characterised by heightened and consistent amounts of pain and fatigue, with individuals often unable to regenerate lost energy except by long periods of sleep. As such chronic illness is a large disruption to an individual's ability to study, and it is imperative that educational settings do vital work with those suffering from chronic illnesses to create adjustments and solutions.

It's also important also to note that chronic illnesses predominantly affect those assigned female at birth, and as such individuals seeking treatment for such illnesses are often ignored or dismissed due to gender biases in treatment. Gender bias in research has also left chronic illnesses tragically understudied².

Other demographic results from the survey may suggest ways in which the DSC struggles to engage with certain groups of students. For example, over 6 times as many undergraduates filled in the survey compared to PhD students. One explanation of this may be that because of the two-union system of Cambridge (CUSU³ and the Graduate Union⁴) that post-graduates are better served by campaigns from the GU, and so are less likely to engage with those from CUSU.

However, in discussing the problem with the GU there is also an issue with how post-graduates in general conceptualise their own disability and how they seek support regarding it. For those whose post-graduate study involves lab research, they may conceptualise that work as a full-time job and consider themselves "bad employees" if they ask for adjustments which make them appear less efficient or capable than non-disabled employees. This then remains an issue that both unions need to work on (the GU has this year introduced a part-time DSO role to their executive) but also that must receive attention from the University and its schools in affirming in its post-graduate students that it is not a "disadvantage" to require adjustments.

Race and ethnicity is also a category where an overwhelming majority of respondents answered that they were either white British or white non-British, with less than 4% of respondents answering from other racial and ethnic categories. The DSC Committee does have a representative BME officer, and CUSU itself has a BME campaign, but it is clear that the DSC must do more to specifically engage disabled BME students in Cambridge.

Indeed, specific and adaptive provisions for BME people have been the source of much discussion and activism both in Cambridge and nationally, from the

² See Jennifer Brea's documentary *Unrest* for a comprehensive exploration and discussion of the failure of global healthcare systems to accommodate chronic illnesses

³ <https://www.cusu.co.uk/>

⁴ <https://www.gradunion.cam.ac.uk/>

work of the CUSU/GU Welfare & Rights officer to allow students to specifically request a BME counsellor, to the Twitter hashtag “#DisabilitySoWhite”⁵ that covers the ways in which whiteness effects how we conceptualise disability.

General Questions

This section was made up of 10 questions designed to gain an overview of students’ broad experiences of their health and care at Cambridge, and how represented and understood they felt within these systems and within other bodies.

The first question asked was “Do you feel that, between different services and staff, you have received adequate care and aid at Cambridge?” with 55% of respondents answering “Somewhat”, 27% “Yes”, and 18% “No”. This was followed by a question where 35% of students felt like there were significant areas of support there were not covered by current services. These areas included: funding, admin & organisational support, chronic illness, extra-curriculars, mental health crises, support on year abroad, issues stemming from teaching, assessment fees, and executive dysfunction. While we can read the 27% “Yes” as a positive statistic, it is evident that there are large areas of disability where students feel unsupported or misunderstood.

Students themselves felt generally able to solve new problems or issues regarding their disability, health, or study as they arose, and most were well informed about support services upon their arrival at Cambridge. Of those who didn’t feel this, they cited their friends and peers, tutorial and college staff, and CUSU as the three main sources of information in finding support.

44% of students felt that there was not good knowledge about support services among the student body in general, with a further 44% feeling there was only somewhat good knowledge. This is emphasised by questions later in the survey regarding awareness about named services, where students said that knowledge was not adequate among the student body for any of these services (the DRC, UCS, and SUAS.)

⁵ <https://twitter.com/search?q=%23disabilitysowhite&src=typd>

The disparity between levels of awareness in respondents and in the general student body could be explained by respondents being disabled students, and thus usually requiring the aid of these services to help facilitate and enable their education and ability to study in a supportive environment. However, while most of the student body may not need these services, it is imperative that we aim to make all students fully aware of them not only in case they should need them themselves at a later date, but in case a friend confides in them and they want to be able to help. Referring someone to a service can be tough if it feels like you are just trying to “get rid” of them, but is also important for establishing boundaries of care, something which CUSU trains JCR & MCR welfare officers on, but which all students could benefit from.

When asked if felt they had sufficient representation as disabled students in their JCR and/or MCR, their Faculty, and their curriculum, the majority of respondents answered “No” to all three of these questions. The final question asked whether students believe it was important to have access to representative practitioners for marginalised groups, to which 77% responded “Yes”. These results emphasise the importance of representation in making individuals feel at home in institutions, but also in allowing them to receive adequate care that they may not receive elsewhere because of cultural boundaries⁶.

⁶ <https://www.cusu.co.uk/articles/success-bme-counsellors>

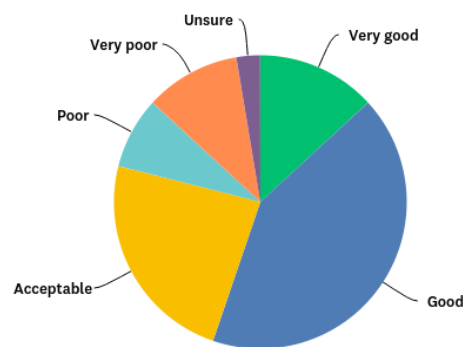
Disability Resource Centre (DRC)

81% of respondents said they had used the DRC⁷, however only 72% they understood what the DRC does. This is only a difference of 4 students, but suggests potential issues with how the service communicates its purpose and activities to its users. Most students also said they hadn't filled in a feedback survey for the DRC when they had used its services.

However, among those who had not used the service the most common reason given was that they didn't want to "take up space", with no students saying they didn't use it because they didn't need it or already had adequate care; thus it should also be part of communications to say not only what it does, but who it is for. A lack of positive identification with disability is a common problem among disabled people, and something that the DSC has worked on this year and which would benefit from further collaboration between the DSC and the DRC.

In ranking their experience of the DRC, student feedback was as follows:

Q32 Overall, how has your experience been of the DRC?



[The image above shows a pie chart representing the percentages of different answers to the question "Overall, how has your experience been of the DRC?" The largest chunk is taken up by the "Good" portion, followed by "Acceptable", "Very good", "Very poor", "Poor", and finally "Unsure"]

The percentages for each response were as follows:

- Good 42.2%

⁷ <http://www.disability.admin.cam.ac.uk/>

- Acceptable 23.7%
- Very Good 13.2%
- Very Poor 10.5%
- Poor 7.9%
- Unsure 2.6%

An 80% majority of respondents did also say that they would recommend the DSC to other students, with 11% saying that they would not.

We also asked students what they liked about their experience of the DRC, and what they feel could help improve the service. A large amount of the positive comments given were directed towards staff, who were described as compassionate, pro-active, knowledgeable, kind, helpful, accommodating, understanding, prompt, professional, and as going above and beyond what students expected of them. Students also valued the non-judgemental environment of the service, and that they felt they never had to “prove” their disability to staff but were actively and sympathetically listened to, trusted, and taken seriously. The DRC’s mentoring service, its aid with exam provision, guidance with homework, and production of student support documents (SSDs) were also mentioned as particularly good elements of the service.

Comments on how the DRC could improve its service for students mainly focused on a couple of key subjects, those being the services’ funding and response time, as well as its distribution and maintenance of SSDs. Many of the comments regarding funding centred on the idea that more funding would mean more staff would mean quicker response times to emails, more consistency between students, and a greater efficiency of the service. Regarding SSDs, students said they would prefer for their SSDs to be written and distributed faster so that their reasonable adjustments can be put into place, but also for the DRC to regularly “check up” to make sure that adjustments are being carried out.

Relating to previously mentioned issues regarding knowledge of the service, many students said they took a long time before contacting the service despite needing it because they were uncertain if it was “for them.” One response in particular mentioned that the DRC should classify mental health difficulties as disabilities to increase the support available to students

suffering with them, however the DRC already does provide support for mental health, and so there is perhaps an issue in how this is communicated.

This forms part of a wider conversation⁸ about the nature of mental health difficulties as disabilities, and while there is some debate about this within disability communities, within an educational setting adjustment and facilitation of mental health is much the same as any other disability, and so it is appropriate and encouraged for the DRC to continue to provide and advertise this support.

University Counselling Service (UCS)

Only 48% of respondents had used the UCS⁹, but 76% were familiar with what the service does, suggesting there is a good awareness of the service among students which does not just stem from personal use. The most common services offered by the UCS that students used were individual counselling (90%), group sessions and workshops (33.3%), and seeing mental health advisors (24%).

Among those who had not used the service, the most common reasons for this were not needing the service (32%), but also not wanting to “take up space” (18%), similar to that of the DRC. Several of the qualitative answers written in the free text “Other” option on the question mentioned the services waiting times as a reason for not applying. When asked if the UCS’s wait times had affected their decision to use the service, 45% of students said “Yes” and 39% said “No”. Most students said they had not filled out a UCS feedback survey after using the service.

Issues of wait times at the service were recently brought to attention by coverage in the student press. While this was acknowledged as a historical issue, and their website states¹⁰ that their “current waiting time is 2-3 weeks depending on availability” this kind of reputational damage has a tendency to linger, especially among student peer support groups. The UCS should then

⁸ <https://www.cusu.co.uk/articles/mental-health-as-a-disability-mental-health-awareness-week>

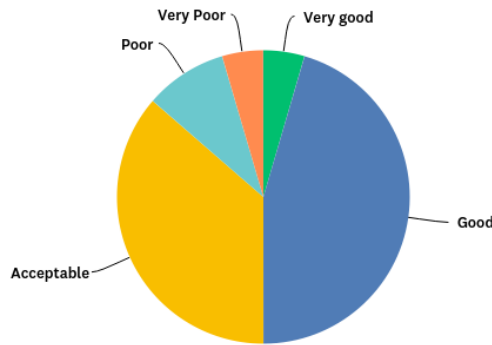
⁹ <https://www.counselling.cam.ac.uk/>

¹⁰ <https://www.counselling.cam.ac.uk/studentcouns/waitingt>

continue its work to “myth bust” the idea of the 6 week waiting list and communicate actively and accurately about its wait times to students.

In ranking their experience of the UCS, student feedback was as follows:

Q45 Overall, how has your experience been of the UCS?



[The image above shows a pie chart representing the percentages of different answers to the question "Overall, how has your experience been of the UCS?" The largest chunk is taken up by the "Good" portion, followed by "Acceptable", "Poor", and "Very good" and "Very poor" jointly]

The percentage of each answer was as follows:

- Good 45%
- Acceptable 36%
- Poor 9%
- Very Good 5%
- Very Poor 5%
- Unsure 0%

63% of students also said they would recommend the UCS to other students, with 25% saying they were unsure. We also asked students what they liked about the UCS and what they could improve the service, with many of the positive comments specifically mentioning the different services and specialists available at the UCS, including the mental health advisors, sexual assault and harassment advisor, and access to a psychiatrist. Students quoted the service as being a much needed source of support outside of their family and friends, and said that their counsellors were positive, understanding, and calm. Methods used by counsellors were also cited, especially the progress

tool used by the service which made “mental health feel much more tangible and measurable”.

Similar to the constructive comments for the DRC, several responses by students as to how the UCS could improve revolved around the services capacity, staffing, and funding. One particular way this manifested was students saying that as they are aware of a perceived strain on the service that they don't use it as they feel they are taking away from others who may need it “more” than they do. In a comment from a respondent this kind of behaviour was also linked to a type of selfless student who downplays their own needs and issues for the benefit of others, then meaning that they are not receiving adequate care. Solving this kind of problem should be an aim of the service going forward.

Other comments related to the knowledge and behaviour of practitioners within the service, specifically that individuals desired counselling regarding their disability and which took their disability into account. This also extended to how their mental health interacts with the other factors of their life, such as gender and race. Longer term counselling and support was also requested, along with counselling that addressed non-academic issues.

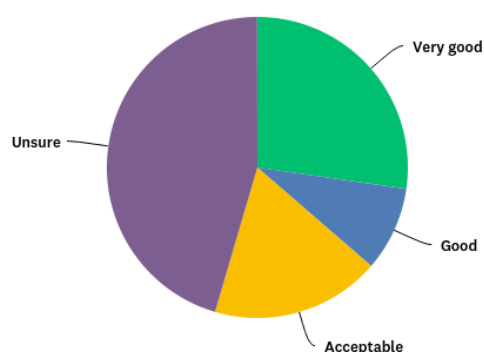
Students Unions' Advice Service (SUAS)

A majority of respondents had not used the SUAS, and a majority did not know what it does, however the combined total of those who were aware and who were somewhat aware was bigger than that of those who weren't. The largest reason for not using the service was not being aware of it, followed by not needing the service. Most students also hadn't accessed any SUAS resources, such as their website, or engaged in any SUAS events, although some students did indicate that they had used the website even if they had not used the service itself.

Despite this, the service is currently experiencing its busiest year on record, and so a possible explanation for these figures is that the service is primarily used by graduate students who are not proportionally represented in the respondents of this survey. However, this is still evidence that awareness of the service could be greatly improved among the student body, and this is a key task for the sabbatical officers of both unions. Among those who were aware of the service, a majority would recommend the SUAS to other students.

In ranking their experience of the SUAS, student feedback was as follows:

Q59 Overall, how was your experience of the SUAS?



[The image above shows a pie chart representing the percentages of different answers to the question "Overall, how has your experience been of the SUAS?" The largest chunk is taken up by the "Unsure" portion, followed by "Very good", "Acceptable", and "Good"]

The percentage of each answer was as follows:

- Unsure 45%
- Very Good 27%
- Acceptable 18%
- Good 9%

We also asked students what they liked about the service, and what they felt could improve it. Aspects highlighted as good were the website, quick response time, non-judgemental advice, removing stress from navigating the university and decision making, and a reassuring presence in meetings. All comments on how to improve the service focused on more awareness and publicity in order to promote a greater access to the survey, and postcarding student pigeonholes was suggested.

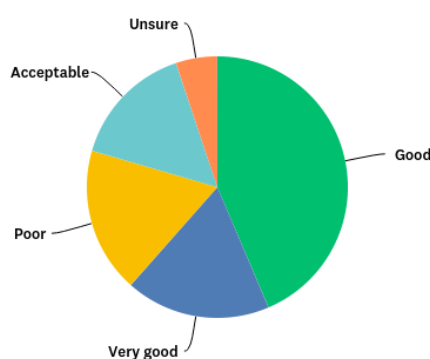
Pastoral Services

This section covered services available at the colleges of responding students.

The first question was multiple choice, and asked which pastoral services were available at the college of those responding. The most common service was a College nurse (98%), followed by a Pastoral tutor (88%), a College counsellor (73%), and a Chaplain (55%). Most students said they used these service occasionally, but significant amount of students also said they used the services often (23%), and rarely (25%).

In ranking their overall experience of these services, student feedback was as follows:

Q71 How has your overall experience of these services been?



[The image above shows a pie chart representing the percentages of different answers to the question "How has your overall experience of these services been?" The largest chunk is taken up by the "Good" portion, followed by "Very good", "Poor", "Acceptable", and "Unsure"]

The percentage of each answer was as follows:

- Good 44%
- Very good 18%
- Poor 18%
- Acceptable 15%
- Unsure 5%

While most students were unsure how to compare college services to those provided elsewhere, large amounts of students did feel that college services were either better or about the same as other services, although most students did believe there was a disparity between pastoral services offered at different colleges. Students felt that they were well informed about available services when they joined the college, but that this was information was not often repeated throughout the year.

We asked respondents a multiple choice question about how they decided whether to use their College's pastoral services, or exterior services from either the University, the NHS, or private care. The three most common factors were quality (64%), convenience (62%), and proximity (38%), with reputation being the lowest at 19%. Other reasons given by students were familiarity, time restraints, complexity of issues, waiting times, availability, and cost.

GP Surgeries

Most students who responded were registered to a GP surgery in Cambridge, which they found to be about the same as their surgery back home, and 60% had no problems switching between their GPs—although it should be noted that 40% having issues is still a significant amount.

Most had used their GP for a disability related issue while at Cambridge, and around 28% of those who did observed significant differences in the way doctors treated them for disability issues as opposed to other times they had been seen by the same doctor.

19% of students had used private healthcare while at Cambridge.

Miscellaneous questions

When asked if anything not covered by this survey had prevented them from receiving adequate care while at Cambridge, students listed:

the social stigma of mental health, financial bureaucracy of colleges, limited funding for transport, unexpected illness during periods of funded study, discrimination from services because of a separate disability, lack of knowledge about neurological disability, long waiting times at Addenbrookes, discrimination from GP, college maintenance staff unwilling to make adjustments, unreliable nature of some services (especially when they consist of one individual), accessibility of the Sidgewick lecture site, reactive action from college rather than proactive, the intermission system, discrimination from academics (despite academic record), additional costs (such as diagnosis), poor pastoral training, 9-5 hours of services making them hard to access for students with rigid timetables.

Most students did not feel able to make change or take action against discrimination based on their disability, and only felt somewhat confident in other people or services to make those changes on their behalf.

Findings

While this is only the first year this survey has been run, and it had a relatively low turnout, some general conclusions can be made from its data. We've also offered suggestions on how these issues could be improved.

1. Minimal awareness of services

All non-pastoral services covered by the survey were perceived to have a low awareness among the student and staff population, thus limiting student's capabilities to seek and receive adequate care and the ability of staff to refer students to it. Services should work to improve their awareness among students, but colleges and departments should also feel an increased responsibility to make staff and students aware of support available to them.

2. Perceived under staffing/ under funding of these services

Most services covered were not perceived to be operating at an ideal capacity, and long wait times and response times either put students off using the service, or resulted in a negative experience and inadequate care. Where possible services should seek to secure more funding to consolidate areas where understaffing may be impacting on efficient access and use of the service. Honest communication with students about how services are funded and operate may also aid students' trust of the service and with its reputation.

3. The cost and complication of being a disabled student

Being disabled involves a lot of paper work, stress, and expense that is largely the burden of the individual student. Colleges and services would do well to provide students with staff support in filling out paperwork and carrying out complex cases.

4. The need for a more competent and coherent understanding of disability among staff and students

Related to the issue of awareness of services, it is evident that the teachers, peers, and support staff of disabled students need a more contemporary, compassionate, and realistic understanding of disability and what it means to

be a disabled student. The Disabled Students' Campaign would be happy to facilitate this kind of discussion/training for interested groups.

5. Inconsistency between services & between colleges

A common issue students face in Cambridge is the disparity of care between colleges, and while it's not an issue that some colleges have great welfare provisions, it is an issue that not all students have access to these services. While the college system complicates anything being universalised at Cambridge, there must be a continued effort in making provisions consistent across colleges.