

Ease of Access to Accommodation Information: Assessment and Commentary for Higher Education and Student Affairs Professionals

Introduction

The ability to pursue and complete postsecondary education can greatly impact the future security, quality of life, and continued survival of individuals who are diagnosed with lifelong health conditions as children and young adults. However, whether or not these individuals may even attempt to pursue higher education often greatly depends on their ability to access accommodations and information regarding these support systems. In 2014, Liz Morasso worked with chronically ill teens and young adults as a clinical social worker at Children's Hospital Los Angeles. Morasso [wrote about the lack of support](#) for disabled students with chronic medical conditions entering college, explaining that, "I regularly struggle to find information on services and eligibility criteria for the estimated 6% to 9% of high school students with a disability who are about to make the transition to college. Most disability offices clearly define eligibility for students with physical, sensory or learning disabilities and mental illness. But it's far less clear how these services and resources pertain to students with chronic illness, especially illnesses that manifest themselves episodically or invisibly." Nine years later, young adults with chronic medical conditions continue to report these same issues.

Access to and the implementation of appropriate accommodations are crucial pieces of the college experience for students with chronic medical conditions. Given that communication with university Disability Offices is typically the first step required for students to access these accommodations, we aimed to assess the ease of access to information regarding accommodations via phone calls to the Disability Offices of community colleges, state-funded universities, and private institutions of higher education in California.

Purpose & Methods

This study was designed by the leadership team at Generation Patient (AKB, SD, and SR), a nonprofit created and led by young adults living with chronic and rare medical conditions. Generation Patient facilitates events, online programs, and advocacy initiatives for this community, with the goal of ensuring that they have the opportunities and resources to thrive. Our study was informed by our own personal experiences accessing accommodations, as well as the experiences of other members within the Generation Patient community. Specifically, we sought to analyze the common themes between various Disability Offices as it pertains to disability documentation processes, accommodations offered, procedures for absenteeism, and dining accommodations. Moreover, since Disability Office staff are likely to be the first individuals on campus to speak with students about their chronic medical conditions, we aimed to understand Office faculty's knowledge of accommodations specific to chronic medical conditions as well as the language surrounding this.

A total of 29 phone calls were made, including 13 to private universities, 7 to two-year community colleges, and 9 to four-year public institutions (including 6 California State University and 3 University of California campuses). Using stratified random sampling and a random number generator, we selected schools from segmented lists of private universities, community colleges, California State Universities, and University of California campuses. Pre-determined *a priori* themes were utilized in the creation of the interview guide with input from AKB, SD, and SR (e.g. accommodation types, registering for accommodations, and attendance/absenteeism).

In order to maintain anonymity and realism, the phone call script was written from the perspective of a prospective student who was diagnosed with a chronic medical condition and thus was interested to learn more about the accommodations offered at that particular institution. AKB conducted four initial pilot phone calls, after which AKB, SD, and SR used an iterative process to adjust questions and phone call foci. We alternated the medical condition that we were calling about, between Crohn's Disease or Postural Orthostatic Tachycardia Syndrome (POTS). All calls were made on weekday afternoons by AKB. The full script can be found in Appendix 1.

Results: Qualifying for Accommodations

Many students with chronic medical conditions may not recognize that their diagnosis would qualify them to register with their school's Disability Office and receive accommodations under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. Thus, in order to assess Disability Office staff's familiarity with the applicability of accommodations for chronic medical conditions, staff were asked, "I am a prospective student, and I am calling to hopefully get some information about the accommodations at your institution. I have [POTS or Crohn's]. I was wondering whether that would qualify me to register with your office?"

We were met with a variety of responses, ranging from prompt assurances that chronic conditions qualify for accommodations to long pauses followed by a blunt, "What's that?" Despite the different replies and response times, all offices did eventually confirm that the condition we were calling about (either Crohn's disease or POTS) did qualify for accommodations. Since the Disability Office is often the first place that students may turn to when seeking appropriate accommodations, it is of the utmost importance that students are met with understanding, support, and knowledge in order to feel empowered to pursue the support services that they need and deserve in order to be successful. If met with hesitancy or doubt upon asking if their medical condition qualifies, the false notions that these students do not belong or aren't "disabled enough" may unintentionally continue to be perpetuated. This is especially true with cases of dynamic or invisible disabilities.

Given this, we recommend that Disability Office staff, particularly those responsible for answering the phones and engaging in a "front-facing" role with students, build more familiarity with chronic medical conditions. Specifically, it would be helpful to explicitly name and give

examples of different chronic medical conditions both on the Disability Office website as well as during staff training. Staff members should also be trained on appropriate language use and tone of voice, so that students are met with respectful assurance of their eligibility for accommodations.

Documentation of Disability

The disability documentation process has previously been identified as a challenge by our community, particularly for young adults with rare diseases and for those whose intersecting identities may contribute to underdiagnosis and lack of access to care. For this reason, we aimed to understand the registration process for accommodations at various schools, including the whether there are particular forms and documentation students need to complete and if there is a specific type of clinician required to complete this documentation depending on the student's disability.

While some institutions required a letter from a clinician, others had a specific form for the clinician to fill out (which was generally found on the Office's website). When asked about whether this documentation had to come from a specific type of health care professional (primary care versus specialty), most Offices indicated that as long as the clinician was aware of the impact of the health condition on the student's "functional limitations," their area of practice did not matter.

These policies can be helpful for individuals who have access to appropriate, specific care. However, it would be remiss not to recognize the limitations surrounding the disability documentation process, including the ways in which classism, sexism, and racism can prevent or greatly prolong the diagnosis of chronic medical conditions. This is particularly compounded by the fact that for students in higher education, the responsibility to seek a diagnosis rests squarely on their shoulders, instead of within the school system itself (as is the case for K-12). Thus, it is important for Disability Offices to receive education related to the limitations in the documentation processes, so that they can better help students navigate this process, particularly those who are undiagnosed but needing accommodations. This can include a more clearly-defined guide about how to obtain this documentation, including providing resources for seeking care at the school's health center or local clinics.

Types of Accommodations Offered

Next, we aimed to understand the types of accommodations that are most commonly offered and available to students with chronic health conditions, by asking "Would you be able to give me an overview of the types of accommodations that are offered to students like me?" The most frequently mentioned accommodation offered was notetaking support, though the mode of this accommodation (via volunteer/classmates, directly from the professor, etc.) varied between institutions. Some of the other less-frequently mentioned accommodations (in response to this

question) included flexible attendance, flexible assignment deadlines, and housing accommodations.

One common theme emphasized during most phone calls was the importance of meeting with a Disability Support Counselor (or equivalent staff member) after disability documentation has

been obtained, for this Counselor to work individually with the student to assess their needs. Some individuals did indicate that they would not be able to provide specific examples of accommodations since they were unsure of what specific accommodations may be helpful for a student with conditions such as Crohn's or POTS.

Though we recognize that accommodations are individual, and thus should be customized depending on the specific needs of each student and the way they experience their health condition, we simultaneously recommend that Disability Offices have tangible examples to provide students that can illustrate the types of accommodation that are offered and may be useful to them. These examples can be particularly helpful and reassuring to students who are newly diagnosed and/or are new to receiving accommodations.

Chronic Absenteeism

Chronic medical conditions are often characterized as “dynamic disabilities” due to their fluctuating nature. This can lead to students experiencing unexpected symptoms and cause them to have variable attendance, which in some cases can lead to chronic absenteeism. To better understand each school's ability to support students in these situations, we asked, “My disease can be kind of unpredictable sometimes, and I don't always know if I'll feel well enough to get to class... What support would you be able to provide me in this case?”

Most Offices indicated that how stringent an attendance policy is and whether a lecture is recorded is largely dependent upon each individual professor. So, while Offices did indicate that flexible attendance could be part of a student's accommodations, many did emphasize that this can be highly variable. Especially in these situations, it is important for the Disability Office to emphasize and affirm to students that they can help be a liaison for their professors in these situations. There is a pervasive lack of understanding about the experiences of students with chronic medical conditions, and this can translate into attendance and recording policies that may not be in the best interest of these students. Given this, it can be helpful for the Disability Office to explicitly offer support for students by helping directly facilitate a conversation with their professors.

Moreover, given that the COVID-19 pandemic has allowed universities to expand their infrastructure and abilities to provide online classes, we recommend that institutions implement system-wide changes to provide lecture recordings for more classes. This includes not only

encouraging or requiring professors to record their lectures, but also providing the tools and equipment in order to do so.

Dietary Concerns

Dietary restrictions were not something that the Offices mentioned as part of their general accommodations, so we also asked about how various dietary needs were addressed. Beyond mentioning that there are gluten-free options (generally, a gluten-free pantry or meal options) available, the majority of the Offices indicated that they were less familiar with these accommodations and that they recommended the student go through Dining Services directly to address any dietary concerns.

While we do understand that Dining Services operates separately from the Disability Office, part of the Disability Office's commitment to students is to advocate for their students, including helping navigate conversations between various entities at the institution. In order to facilitate this and to ensure that students with dietary needs are accommodated appropriately, Disability Offices should have a specific liaison or communication process between themselves and Dining Services. This would alleviate the burden placed on students to reach out to separate organizations within their institution, in order to have their access needs met.

Role of Disability Support Staff

Finally, to wrap up the calls, we asked what the person's role was at the Disability Office. While some Disability Counselors did answer the call, the majority of calls were answered by an administrative assistant, scheduler, or other equivalent. Particularly at the smaller, private institutions, the person answering the phone did not exclusively work within Disability Services, but rather was part of a more general, multi-disciplinary student affairs team. It is to be noted that in some cases, the phone went straight to voicemail. Some recorded voicemail mailbox greetings indicated that email was the best way to reach out to their Office, while others indicated that they did not have a live answering service, but someone would call back if a voicemail is left.

Given this, along with the fact that not all schools had a designated/separate office, person, or phone number to call in order to discuss accommodations, it may be more efficient for students to first reach out via email, to ensure that their questions are directed to the appropriate people who can help. That being said, we recognize that phone calls can appear to be the quickest way to receive answers or get some preliminary information. Given this, we believe that it would be helpful for all front-facing staff members to be trained not only on the specific resources that are offered to students, but also on appropriate and compassionate tone and language use.

We also recommend that Disability Offices make it clear on their websites (and other informational materials) whom the appropriate person is to contact and through which method

(such as email, phone, an online form, etc.). This would make the information and registration processes more efficient for both students and staff.

Conclusions and Key Recommendations

In summary, given the crucial role of accommodations in ensuring the success of students with chronic medical conditions in higher education, we recommend that the following steps be taken and considered by Disability Office leadership and staff.

- First, Disability Offices should provide easy access to clear information regarding disability services, accommodations, and related processes, as well as appropriate and reliable contact information on the university website is essential. We would suggest
- including examples of chronic medical conditions for students who may not realize that their condition qualifies them to receive support services through the Disability Office.
- It is also critical that any Disability Office staff that may be interacting with prospective or incoming students be educated on chronic medical conditions, appropriate language use, and demeanor.
- Furthermore, proper training and education on the needs of students with chronic medical disabilities should extend to all university staff to create a truly accessible and supportive learning environment across campus. More specifically, providing faculty with a better understanding of the unreliable nature of such conditions (particularly dynamic and unapparent conditions) and challenges that result such as chronic absenteeism, as well as needs for flexible education options, reduced course loads, and beyond. This information may help to encourage faculty and administrators to implement policies and behaviors that will allow for creative solutions to the unique problems currently faced by these students.
- Finally, we would encourage college disability offices and advisors to act proactively as advocates on behalf of students with chronic medical conditions by working as communication liaisons between students and any areas of the university that plays a role in their accommodations including but not limited to professors, department heads, dining services, health services, and more.

Currently, young adults with chronic illness face unique challenges within institutions of higher education, which impacts their ability to attain both educational and career opportunities and, by extension, their future independence and quality of life. By working to implement changes like those outlined above, universities can make secondary education more accessible to individuals living with chronic medical conditions before they are even officially enrolled and ensure their students are equipped with the necessary support to complete their educational goals.