Disclosure and Accommodations: Considering the Disabled Academic Experience

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The academy is not known for being kind. Nor is it known for being flexible. For me it was also almost my downfall. I followed the steps. I registered my disability. I paid for the forms from the doctors proving what I needed. I did it months in advance of the semester.

First lecture of the semester: I am exhausted. My brain is foggy, and my limbs feel like they are swimming in pudding. I have done all the readings and have detailed notes, keywords, and important quotes highlighted. My summaries of each article have been diligently entered into my reference manager. I attend the lecture and even with all my preparation cannot recall a single thing that was said. I view the recording and find I have zero recall of the lecture content. Having been in the room I know that the lecturer walks around the space. Their voice fades in and out on the recording. I listen intently, making detailed notes on the parts I can hear. "Yes, exactly!" I hear the instructor say as they seem to be returning to the lectern. The slide gives me no context as it is just a block quote from the reading. "That will definitely be on your final." "WHAT WILL?," I shout at the screen.

This is an average day. Lecture slides that don't match the discussion. Dialogue I cannot hear. I attended in person, but my brain didn't work, and the recording seems to offer only whispers from the back of the lecture hall. I have now dedicated four hours to attending this 2-hour lecture and still don't know what will be on the final. I read through everything again, trying to weave it together with the other readings and the lecture slides. I wade through the context clues; yet, I still don't see the connection.

Since the lecture is recorded, a part of my accommodations has been granted; still, the lack of captions or transcript and the missing microphone leave me struggling. It is too late now. The lecture is delivered. I send an email to the lecturer asking them to repeat student questions and comments made away from the dais so the recordings can capture them. They respond that they will try, but these rooms aren't designed for recording, there's never a microphone, and it would be disruptive to the class attending in person to repeat everything for a recording. I read the subtext realising my needs don't matter.

There are 100 students registered in this class and more than 60 are listed as online only. Who knows how many other accommodations are missed? The course was not designed for us.

Creating the Environment

Inclusive learning requires instructors to teach with disability in mind. To create an inclusive learning environment,

educators must be willing to stretch beyond their specialties to meet students where they are. This often means faculty must engage with learning pedagogy, new technology, and methods outside of their discipline. In this essay, I encourage academics to consider inclusive education by using universal design in their class modules, and to wield their institutional power in a way that supports a diverse student body. Unfortunately, in the current climate, this labor is something most educators do not have the capacity to do.

The academy is inherently ableist. The current default course design caters to those who have no need for physical or intellectual accommodations. It is also racist, classist, and rife with other systems of domination that reinforce power and status quo. In addition, the physicality and intellectual standard of default course design is ableist and exclusionary; and it is critical to consider how it is impacted through intersectional experiences with others like it. This work explores the challenges of disability disclosures and accommodations, as well as the labor they require. Ultimately, I ask educators to do better for students and peers within the academy, while being kind to ourselves. To limit the scope, I explore just two factors of the disabled student experience: the disclosure and accommodation request, and accommodations within teaching modules. While doing this, I recognize that ensuring accommodations are met as requested often involves a complex web of systems and resources that intersect across departments and disciplines.

My own experience is wrapped in privilege. I kept my disabilities hidden in my workplaces until I was forced —and many others, as Helena Liu reminds us—to out ourselves during the pandemic.[1] Today, I am fiscally secure, white, cis-gendered, educated, live in a safe, warm home, and have a support network around me, all of which are advantages that aid me in disclosing and limit the ramifications faced by others. Putting on a public façade to segregate my home and work/school lives comes from my formative years where the emotional, physical, and substance abuses in my home were "something we don't talk about." At a personal cost, both mental and physical, I have successfully hidden my limitations regarding neurodiversity, mental health, and physical illness by adapting my behaviors to appear "typical" in my places of work—commonly referred to as "masking"—for decades, only to pay a price for the misuse of energy later.

I am motivated to serve the student experience because my own has been laced with behaviors such as masking and outworking to camouflage in academic spaces. So, why should I disclose in such a public way? The answer is three-fold. First, I disclose because the cost to me is less than it is to others, particularly those who have compounding experiences. Second, because my voice is often heard when I am in positions of power or spaces of influence. Third, I disclose because if I do not work to care for those who *most* need support, I am not the person I am trying to be. It is people like me who can force the hand of change. I openly acknowledge my privilege and aim to use it as a weapon of inclusion. And critically, the literature in this field—including work by scholars such as Sara Ahmed, Jay Dolmage, Katherine Aquino and Joshua Bittinger—reinforces the impact actions like this can have.[2]

A disability-focused lens exposes risks, as personal data and medical diagnosis tangle themselves in the email and Learning Management Systems (LMS) that drive daily academic life, and labor as academics and faculty attempt to document and track student data. I want to recognize that many people do not have the luxury of choosing *when* or *if* they disclose their disabilities. Many disabled individuals cannot hide their use of physical or cognitive aids by masking to blend in with those who are "typical." I use the term "typical" to highlight the accommodations *disabled* individuals require that vary from the status quo. In many cases scholars use the term "normal," but with more than 25% of our population already identified as having a disability, "normal" is dismissive of an increasingly common disabled experience.

Disclosures are both systems-driven and pedagogically motivated. However, to protect both the institution and the student, disclosures and accommodations must have parameters in place to ensure academic integrity and personal data protections are honored. Disability disclosures sit in between pedagogy and policy, while accommodation requests are simultaneously a pedagogy exercise and a human rights issue that has moral, ethical, and legal consequences. As has been pointed out in the work of Fredrick Nafukho, Richard Rosseler, and Kit Kacirek, disability is a powerful component of diversity.[3] I acknowledge that each institution has different processes, and as a migrant who has studied on three continents, I have learned that legal requirements that surround the use of personal data and granting accommodation varies greatly. As such, I have used generalizations regarding labor and tasks which might not be a match to all institutions.

My primary focus is serving the disabled student. I do also acknowledge that many disabled staff experience similar obstacles. Liu and Ahmed articulate the varied ways disabled academics may find their careers at risk by exposing vulnerabilities to peers and institutional leadership.[4] This likely sounds like an argument for accommodations being built into course design, and of course it is. However, creating an accommodation- and disability-inclusive practice goes beyond the student experience. In this work, I hope to build upon the work of scholars like Zoë Ayers and Aimee Simpson et al. to demonstrate some of the labor that is happening behind the scenes in the calendars and inboxes of faculty who are likely to be precariously employed and struggling themselves.[5]

Disclosure

Disclosures are inherently messy. The systems and processes in place today require a disabled student to disclose their disability—often supporting it with numerous medical and legal forms—and ask for relevant accommodations. In many cases, students are required to repeat this process tens, if not hundreds, of times throughout their academic journey. Each time that data gets moved from person to system it places the individual and the institution at risk. This is not to deny that inclusion is an incredibly worthy goal, but to point out that disabled students are forced to disclose private details that those who present as typical do not.

Disclosing disabilities costs students time and money. The act of disclosing disability to an institution to garner accommodations comes at a cost to both the disabled person and the institution, and it places the disabled person at risk of discrimination despite their legal rights to receiving support. There are multiple layers to a disclosure before beginning to consider individual accommodations; these include what data is required, collecting disclosure details in institution-specific formats, and how data gets accessed and shared. Additionally, there is a social layer as we question why the most common accommodations are not automatically built into every program design in the first place.

Disability disclosures are costly to the individuals involved and in hard currency of time and labor for universities. They involve asking those—in some cases those who are not of legal age—to disclose medical information through channels that are neither secure nor controlled in any way. It opens the university up to legal ramifications if details are misused, the disabled person to abuses of power as they hand over their needs to lecturers and administrators, and other risks too extensive to mention in this forum.

Disclosing disabilities adds to the workload. In their work on disability, Leah Piepzna-Samarasinha found that for many—myself included—acknowledging disabilities requires not just medical diagnosis, but labor to unwind existing ableist thought patterns; indeed, decades of gaslighting and ill-treatment suggest people misuse or abuse medical systems when seeking care.[6] This history often adds to the struggle to request accommodations even once individuals have arrived at a diagnosis. Building onto the already significant workload is an additional burden that comes from disclosure: handing over power to someone who may hold their disability against them later.[7] Ethically, I do not have to disclose; none of us do. Nevertheless, since the systems and processes are designed for typical behaviors and abled bodies, if I do not request accommodations, I suffer from ableist systems and program designs.[8] The institution and the lecturer are no worse for wear.

Disclosing disabilities is work for students and instructors. The disclosure itself requires significant labor before any action to support the student has occurred. This labor is two-sided, of course. Firstly, the disabled student is required to work towards meeting all the policy and program requirements to certify their disability with an administrative office that is likely not tied to their academic course load. Secondly, the institutional staff must work to manage the disclosure and govern the related data before beginning to accommodate needs. I use the term 'accommodations' to include any adjustments to content delivery, assistive tools, or additional access to information that may be required to ensure a positive experience is delivered. I will explore each of these in turn.

Students with disabilities often find themselves in a world that has not been built with difference in mind. This means that disabled people must learn how they are different, and how systems are structured, before discerning how they might best be accommodated, often on a course-by-course basis. Ahmed highlights that when an individual does not fit a structure they must escalate with a complaint (accommodation request) or suffer in silence. She writes: "You learn how a structure is

built when you do not fit in that structure. A complaint can be what you do *not* have to make if you fit, if you are enabled by a structure."[9]

The disabled student must become their own advocate. Each disabled student is responsible for their own experience and advocacy within academic contexts, though I recognize some may have parents who complete these tasks on the student's behalf. Labor pushed onto students often include fiscal costs: specialist appointments, letters, transportation; time penalties: effort to get to appointments and delays experienced due to scheduling obstacles, time spent advocating for accommodations, additional time required for task completion; education: towards their care providers, their leadership, and peers. Each of these penalties exist outside the core skill delivery of getting an education. Further, as Dolmage puts it: "another entailment of the accommodation model is the idea that it is the student him or herself who must prove that they need accommodations, and argue for them reasonably."[10]

Documenting disabilities is different at each institution. Getting a disability and list of needs documented is not an easy feat. This is particularly complex when an individual has yet to receive a definitive diagnosis for symptoms. It is worsened within a global healthcare system that is suffering from long wait times and expensive service costs for private care. It is not uncommon for a person to spend a decade seeking a complex diagnosis.[11] Additionally, there is the time and energy needed to attend specialist appointments, the cost of getting to them, the emotional turmoil of getting (and in many cases not getting) a diagnosis, medical gaslighting, racism, and so on.

In my experience getting a diagnosis—not including the care required once attained—took months of appointments. I estimate that between booking, travelling, and attending appointments, I spent at least an hour a week for more than six months getting diagnosed, in addition to a personal cost of thousands of dollars. This doesn't include the regular health care efforts of standard check-ups, blood work, etc., and frequent follow-ups after diagnosis. All of this also must be considered in any medical journey. Assuming a disabled person has a diagnosis, they will still have to request, inform, and possibly educate each person they require accommodations from. Another possible cost: the labor to follow up, lodge complaints, and escalate within the institutional systems if accommodation requests are not honored.[12]

In many cases, these hours of labor to prove a need for accommodations and to create a compelling argument for them require the student to understand legal, institutional, and medical systems their peers have no need to know even exist. These efforts appear in a multilayered system where a student or faculty member must first know what they require and then learn the system and related policy to acquire the accommodation, all before needing to advocate for, and in many cases, instruct those in positions of power on how to engage with the accommodation. For many disabled people, this labor exists as an unpaid side job where they must navigate their needs in a gray space that takes untold hours and energy that are not able to be directed toward their academic work. This can be particularly taxing as the student moves across courses that require a wide variety of accommodation types due to the course design or materials being covered. It is my experience that the Covid-19

pandemic has exacerbated this conduct as access was at once extended to include inclusive tactics such as hybrid approaches, close captioned recordings, and flexible timelines, only to be rescinded when administrators pushed to bring students and staff alike back onto campuses.

Moving data around is risky. Mechanically, passing what is often personal medical information around via email is treacherous. Legally, there are controls on sharing data and giving consent as to its use, which I would argue is not something most academics are knowledgeable in. Further, those in receipt of this data are at risk of forwarding the wrong email to the wrong place and exposing private data even further. Morally, most would argue that personal medical details shared with someone in a position of power could influence your experience negatively. Both Amy Allen and Steven Lukes discuss what can go wrong when power is misused, and the damages are astounding.[13] Many might hope to rarely encounter a bad actor; but in most of the academic spaces I have been engaged in, crushing others for prestige is common behavior. Unfortunately, this has been the case for decades in workplaces where individuals who have disclosed disabilitie—to human resource departments and managers—are let go under the guise of other, seemingly benign reasons.[14] It cannot be denied that this has infected academic practices, as well.[15]

Accommodations

Delivering common accommodations is not easy. Accommodations are complex and varied. For example, some students may need to ensure a refrigerator is made available for medications. Some require alternative methods to access a lecture or need learning supports such as note-taking. Others may need provisions or extensions in place while they deal with medical challenges. Once all the required documentation has been completed, the onus is on the student to ensure they receive the support they have requested. An accommodation requesting that a lecturer wear a microphone for recorded lectures cannot be ensured until the lecture has already been delivered and recorded. The student must then circle back to either their disability office or the lecturer to reiterate their accommodation needs, a process that often happens via email. This creates a gap between the experiences of typical and disabled student that often widens as the semester progresses.

Accommodating a student's particular needs can range greatly. In some cases, this might be as simple as a flexible delivery date for assignments, or as time-consuming as manually adding verbatim transcripts to digital lectures, or as complex as adjusting and sometimes completely rebuilding content and course materials to account for areas of difference. However, even for a simple case like a flexible submission, there is a cost to both sides. The instructor will have to update relevant LMS systems with a new date for this student to avoid automatic penalties and will likely have to spend time outside of their normal marking schedule to complete the assessment when it arrives.

Consider the number of accommodations requested for each course a lecturer teaches and the different needs of each student. Of course, all of this information cannot be studied by a lecturer until after

the disabled person has completed working with the Disability Office (DO) or equivalent ADA or department-level body to get their disclosures on file. Understandably, many would argue that the student taking a full course load does not add labor to the DO in direct relation to every course. However, this does not account for those students who need deep coordination such as note-taking, transcripts, room changes for mobility-device-friendly classrooms, etc. Each of these more complex circumstances commonly involves multiple departments and experts to work together—a task that, again, is commonly completed via email.

When policies are created, they are often linked to others. This interdependent web of rules, processes, and accountabilities impact staff, systems, administrators, and students; and this is where the ethics of disclosure live and breathe. An instructor cannot change the rules for a student in the middle of the semester in such a way that unfairly disadvantages their peers. But if a course, program, or policy is designed in such a way as to unfairly disadvantage a disabled person, does it not warrant rebuilding?

If the lecturer understands the disabled person's needs, a single informative email from the student might be all that is required. In a course with 60 students and an average of 25% of the population (United States and New Zealand) identified as having a disability, that means perhaps fifteen of these emails per course.[16] In perpetuity. For an instructor carrying between eight to ten courses a year, these labors grow exponentially. It is my experience that emails are a plague in the academy. Intelligent people who are overly committed and receiving hundreds of emails each day are bound to miss some; thus the student needs to follow up more than once.

The scenario becomes more complex when a disabled person discloses a specific set of needs. There may be a meeting required, which would likely be coordinated through the back and forth of emails. There may be additional resources and referrals within the institution required. Each scenario is unique, but the labor varies given how accommodating the course design was to begin with.

Acknowledging the large percentage of disabled students is of course the first step. This needs to be quickly followed with pedagogical training on inclusive learning design approaches. Delivering on a social good has been at the heart of disability and inclusion tactics since the very beginning, but inclusion is a moving target. To respond to these challenges, pedagogical scholar Katie Novak suggests instructors work to develop course materials that take the most common disability accommodations into account using Universal Design for Learning (UDL), thus responding to the accommodation request before it has occurred, saving time and energy for the course delivery itself.[17] In addition to UDL, there are movements for inclusive teaching and learning strategies, varying widely from Susan Blum's approach to ungrading to what Kevin Gannon and Jay Dolmage consider educating using empathy.[18] And I would be remiss to ignore the vast efforts of people of color and Indigenous academics seeking to make the colonial academy a place where students can thrive.[19]

Inclusive Pedagogy

Using inclusive pedagogy requires training. Delivering inclusive content requires training and re-training for academics and faculty on how to serve students and build educational materials. Using UDL solves some of the gaps in the structure of class and program execution. For some students this might be the request of an instructor wearing a microphone or adding subtitles/transcripts to content to aid speech comprehension, while another might need images to be described in text media such as readings and lecture slides. Doing these tasks automatically via UDL means that those requests are already granted for a student who has a documented accommodation need, but this technique will also serve an instructor's other students.[20] By considering the most common structural gaps in course design, faculty can reduce the load on themselves and their students with documented disabilities while simultaneously benefiting other students with inclusive learning design.

Learn the barriers students face. Novak uses the metaphor of a menu in their work, suggesting that educators plan the menu of learning outcomes and begin breaking down the dishes required: slides, exercises, readings, videos, etc. Then educators must work through the tools people will need to access them: recordings, text overlays, microphones for sound clarity, transcripts, and so on to ensure that they are "eliminating barriers so every student can succeed."[21] While this learning menu removes many barriers to accessing the knowledge and course materials, it doesn't account for cognitive differences such as dyslexia, reading comprehension/speed—particularly for second language students—or challenges such as students having the "executive function to set the goals, plan their projects etc."[22] Many of these areas of difference require you to consider the fonts you select and the length of materials you are asking students to review.

Empathy makes for a better teacher. In my experience this is where the empathy that Gannon advocates can come into play, which for many requires a lecturer personally engaging with the student. The most common empathetic accommodation for those going through a hard time academically or personally—extra delivery time for assignments—can also be planned for in learning design. Turning acceptance criteria on in an LMS beyond the due date can turn requests into an automatic yes, saving both the student and lecturer labor. Granted, this doesn't serve all elements, but offering a chance to submit late without penalty can be a gift of grace to students.

Cheaper is not better. The neoliberal university has focused on removing social responsibility that serves the social good in exchange of cheaper alternatives that often are not fit for purpose.[23] Notably, this seems to have included a reliance on poorly designed technological solutions that don't always help, while some are actively hindering disabled students. In the end, the labors to manually adjust systems and processes to accommodate student needs on a case-by-case basis impact individual academics who likely do not have the time, capacity, or skills to execute on them well. These "ambulance at the bottom of the hill"

processes are built upon the heart of the colonial institution, which has also done considerable damage to those scholars who are queer, Indigenous, and people of color who enter these environments only to experience intergenerational trauma at the hands of the academy.[24]

Arguably, manual processes are a cost-cutting measure that reinforces ableist values, and placing ownership for validating accommodations on disabled people is a perfect example of how a systemic problem has been outsourced to those who are hurt by it, leaving those who are unaffected to carry on with their lives.[25] While there should not need to be additional efforts to have disabled people's needs included in educational design, today there is. It is critical to consider the labors of an arguably overworked and undercompensated workforce in this regard. Academics are experiencing increased precarity and underemployment in an environment where many individuals are piecing together a career made of short-term contracts.[26]

Conclusion

Meet student needs to help them succeed. An individual who has their needs met can focus on their academic endeavors more easily. And since 25% of the student body likely has additional needs, by not adding accommodations to learning design, educators are effectively leaving them behind and missing out on their talents. Recall the story I opened with: I had done everything right but still found myself and many of my peers left behind. Fear of the risks caused by ableism can create a chain of events that cause students like us to hide our divergence, avoid self-advocacy, and struggle for the duration of our adult lives.

Leading with inclusion saves time and energy and showcases a widening awareness of our changing world. In the wise words of Piepzna-Samarasinha: "we won't be able to create the just future we all still hope will show up, without disability justice and disabled skills."[27] I offer this quote as a motivation to create learning journeys to help craft the inclusive future we all deserve. In this environment I understand how hard it can be to even consider reworking course materials or navigating a badly designed LMS to increase accessibility, but any movement forward is *still* advancement. Progress, not perfection, should be the goal.

Author's note: For insights into disability justice from queer and BIPOC viewpoints, I recommend diving into Leah Lakshmi Piepzna-Samarasinha's "The Future is Disabled" and Alice Wong's Disability Visibility Project at https://disabilityvisibilityproject.com/.

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