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The violent consequences of disclosure...and how disabled and mad students are pushing back

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Introduction

Disclosing disability is a complicated and challenging process in higher education (Matthew, 2009; Cheuk, 2012; Kerschbaum, Eisenman, and Jones, 2017). It includes submitting medical documentation, participating in assessments with disability service officers and medical experts, and arranging accommodations with professors and teaching assistants (Olney & Brockelman, 2003). Although disability service officers do conduct parts of the disclosure process in private, and students' medical information is legally protected in many countries, there still exists an onus on students to reveal more information than is required to secure their guaranteed accommodations. Disclosure over email and in one-on-one conversations with teaching staff and administrators can lead to cases where students feel obligated to describe their disabilities or psychiatric differences as a way to ensure access to their learning. The consequences of this process for many disabled and mad students are experiences of violence (for explanation of language choice, please see Titchkosky, 2001 and Reaume, 2002).

By violence, I refer to the institutional violence that is a result of having to engage in a system that relies on the uneven exchange of private and personal medical information for access to the necessary equipment and support to be successful in higher education. This violence is a consequence of the obscure, risky, and often complex nature of the disclosure process, and for disabled and mad students who are transitioning from high school or who have acquired an impairment or diagnosis during their time in higher education. Understanding this process is often necessary for their success in this sometimes-violent space (Price, 2010). More importantly, however, students should be aware that there are opportunities to subvert these violent processes by working collaboratively with faculty to ensure access to their education.

Faculty and administrators, too, should acknowledge their role in maintaining this violence and work towards dismantling it to be replaced with other possibilities.

Similar to the experiences of those I interviewed for my research, many of my experiences of disclosure in higher education were violent (Shanouda, forthcoming). They include differential treatment where professors, instead of teaching assistants, grade my work; disability officers denying my requests for accommodations “because,” they would say, “I had already made it this far without them”; and, administrators requiring new psycho-educational assessments, although my disability is permanent and my paperwork was up-to-date. In addition to these more serious experiences, I also navigated accusations made by teaching staff and disability service officers that I was malingering or lying, and they made attempts to limit the number of accommodations I could ask for. In the process of collecting data for my research project, I discovered that these experiences are almost pervasive.

What follows is a collection of narratives and quotes from disabled and mad students on their experiences of disclosure, passing, and coming out. The narratives, as tightly constructed stories, provide readers with layers of information, such as the connections between experiences, as well as the consequences those experiences had on students. These stories challenge current practices around disclosure and demand a critical reflection of those practices. They illustrate how the requirement for disclosure opens up a space for violent interactions in higher education. These stories also describe both the immediate and on-going consequences of disclosure to both visibly and non-visibly disabled and mad students. In addition to the emotional and physical toll of experiencing violence, the consequences of disclosure for many participants were severe – with some dropping courses, others changing programs, and one student (from those quoted below) dropping out for a year. These students, however, also describe how they questioned the current process and pushed back to ensure their continued presence in higher education

Disabled and mad students entering academia, or those who will acquire an impairment or diagnosis during their time in higher education, need to understand the potentially harmful impact that disclosure may have on them. Not all interactions will be violent, but some will and these interactions will stay with you, as they have for the participants I interviewed. They will inform your understanding of disability and madness and shape how, when, where, and to whom

you will feel comfortable sharing your story of difference. In your capacity as a student, however, there is creative potential to undermine this process, subvert the requirements, and challenge the accommodations structure in higher education. Doing so means finding allies and champions amongst members of the teaching staff and in the administration. However, it is also the responsibility of faculty and staff to make themselves known to you by calling out the violence of disclosure in their departments and faculties and in the classroom and by working alongside students to remove the requirement for disclosure in higher education.

Requiring Disclosure: A Violent Process

Irene's narrative encapsulates how disclosure is an inherently violent process in higher education. When finalizing a modification for their qualifying exam (or comprehensive exam), Irene is forced to disclose intimate experiences from their childhood:

The accommodations requested seemed reasonable to everyone involved – their supervisor, committee members, their peers, the department administration – everyone. Except, in order to sanction the modification, Irene would have to go through Accessibility Services. Irene says the department needed some backup, “[...] need[ed] the paperwork”. The consequences of this bureaucratic desire led to real consequences. Irene’s therapist was not accepted as a reference by the disability service officer – something to do with their professional title. It didn’t seem to matter that this was Irene’s choice of referee and that this therapist could speak expertly to their need for specific modifications. Irene was forced, therefore, to see a general practitioner (GP), who would then refer them to a psychologist or a therapist who could sign off on the paperwork. During her appointment, Irene was forced to disclose intimate experiences of childhood sexual violence. In exchange, Irene received 3-extra days to complete their exam.

Irene relayed this incident and argued that this “process [of disclosure] was kind of re-traumatizing.” In addition to illustrating how the disclosure process can lead to experiences of violence and trauma, Irene's narrative also demonstrates that accommodations are often simple requests – extensions, extra time, assignment modifications; requests that can often be managed in the classroom or among a group of trained faculty members. Accommodation requests can

become unnecessarily complicated however—as in Irene’s case—when the demand for medical and bureaucratic approval is disproportionate to the request (Samuels, 2014). Irene had to tell their story in exchange for 3-extra days—a modification that could be granted without having to engage with the university’s mandated policies. The exchange of information for access, in this example, as in many, is unfairly skewed.

The consequences of the disclosure process, however, are not always immediate. Moana’s narrative illustrates how she experienced various violent consequences throughout the semester after disclosing to a professor before the start of class.

I met her in December—a month before the class was meant to start. I thought I was being proactive and responsible. She didn’t seem to see it that way. I told her about my disability – anxiety, heart condition, learning disability, etc. She seemed annoyed – or something like that. She kept asking me, “What do you want me to do about it?” She followed that up with, “You can’t be missing class because this is an acting course.” I thought, “Who said anything about missing class?” It seemed to me that she didn’t really understand her role in this process. The class was hell. I was constantly frustrated – often tearing up – unsure of her requests or direction. She threatened me in front of the whole class. She would yell, “I can take your acting card away.” I was scared after this point. I continued going to class, but things were weird, tense, and generally unpleasant moving forward. I was upset because I felt like I was letting her down. Her parting gift to me, and only me, was a personal assessment. To sum it up, she suggested that I quit acting. Her exact words were, “You should reconsider your future in this field.”

In disclosing, Moana did not secure her accommodations nor was the classroom made more accessible. Instead, immediately after she disclosed, Moana was characterized as indolent – “you can’t be missing class” – and throughout the semester she was threatened, yelled at, and told to change careers. Disclosure, as illustrated by Moana’s quote, is not just a single encounter a student has with their professor or teaching assistant, but can be an on-going process that has a long-lasting effect (Miller, 2015).

Both Irene's and Moana’s disabilities are non-visible. Students with non-visible disabilities have a more challenging time disclosing disability because their unrecognizable

differences require them to meet a higher burden of proof (Samuels, 2003). However, the violence of disclosure – its violent consequences – also impact visibly disabled students. After having neck surgery to remove a mass, Jimmy's teaching assistant denied him an extension. Jimmy then visited the teaching assistant:

Jimmy: It was such a nightmare. He was so... I don't want to say hostile, but he just like ... it just seemed like every time I opened my mouth or sent him an email I was like personally going out of my way to inconvenience him, when in fact I was doing everything I could do to be like the most ... meek and mild-mannered. And I'm already a fairly mild-mannered person, but like I was trying to be ... I was trying to be as small as I possibly could. Like this little mouse that they would have pity on and give an extension. But it eventually got to a point where I actually had to go this TA's office while I still had a drainage tube in my neck. [...] This tube, with like fluid draining out of my neck. It was definitely, it was like physically uncomfortable... But like I had to go down to [school] and talk to him. And he was like, "Write a little blurb to me about why you're requesting an additional extension." And I was like, "Fine. I'll do that." And I went to great detail just to kind of like make a point, like do you really need to know ...

Disclosure is therefore also a part of visibly disabled and mad students experiences in higher education. They too have to be “authenticated” by the institution by handing in paperwork and registering, even though their differences are visibly apparent. Jimmy, under these circumstances and compounded with the stress of keeping up with classes and the extensions granted on other work, dropped out of school for the year. Having to leave school was a significant consequence; one that is potentially overlooked by institutions because, unlike Jimmy, some students never return (O’Keeffe, 2013).

A Systemic Violence

Experiences of violence during disclosure are not limited to the classroom setting; rather, as Evadnae describes below, disability service officers and the intake process itself can be a distressing experience (Goode, 2007). Evadnae explains here what it means to have disability service officers advise her to drop her courses after she sought support:

When I got my first intake when the ... person I spoke to was just like, “Yeah. So, have you considered dropping some of your courses?” And I’m like, “No. Why would I consider that?” And then she was just like, “Well, like I think that might be better for you.” I’m like, “I didn’t come in here for your opinion on what ... might be better for me. Like, I know what I’m doing. I just feel like this office should try to aid me in that, in trying to accomplish my goals. And I understand that there is a particular negotiation with taking on more than you can handle. [...] Or the emails that stand out the most for me from [disability service offices] is like, “Make sure you drop those courses. Make sure you like, you know, do it before the deadline so like xyz doesn’t happen.” And I’m just like, I don’t think that this is the right approach, but I mean....

Counsellors or advisors are meant to help or provide support and guide students through higher education; however, as Evadnae’s experience demonstrates, the focus is not on creating a more accessible and inclusive environment for diverse learners, but rather on molding the individual to fit into a preconceived notion of what constitutes a successful student (Shanouda, forthcoming). The construction of this ‘normal’ student influences disabled and mad student’s self-perception and is possibly the most severe personal consequence that results from having to engage in the disclosing process. Here Fernando explains how these normative ideals influence him:

Being told you're inadequate by a system that seems like it's not built for you to the point where you start to think, “Well this is so entrenched that it can't possibly be wrong.” So, therefore, there must be something wrong with me...and sure there was something wrong, perhaps. [...] Like who wants to admit that they need extra help in a class. You’re supposed to ... You’re a university student. You’re supposed to like have your shit together. You’re supposed to be smart. You’re supposed to be conscientious. You should be lucky that you’re in that- you should feel lucky that you’re in that classroom. But I wouldn't say that I was the problem. I would say that it was a problem of the systemic barrier that was the big issue. [...] We need to myth bust the representation of the normal student.

Fernando describes how disabled and mad students might feel as a result of having to navigate and disclose in a system that defines their way of being and learning as inadequate. Having to disclose in an environment, such as this, means that very few encounters lead to anything other than experiences of violence. Fernando also starts another important conversation in this statement: that moving forward means acknowledging that this normative context exists and that students and administrators need to work together to address the harmful consequences of the current system.

Subverting Disclosure

Disabled and mad students have always found ways of subverting the disclosure process and accompanying requests for ‘the paperwork.’ Participants indicated that they learned early on in their academic careers that when they revealed more information than what is considered appropriate they could avoid these requests. Theresa explains how this process was still violent, but that at the very least it meant she could avoid the bureaucratic hassle:

And then yeah, a lot of times I found the only way to get extensions, or to get like a late withdrawal, or something, from a course was to disclose more than I was actually comfortable with. But it was the only way to really ... to really get it done. A lot of times in like ... yeah, if you say, “I had a suicide attempt,” it’s super shocking and its way more information than you necessarily want to put out there, but at least you won’t have to be fighting about it for the next six months.

Some students have always subverted the disclosure process (Sierra-Zarella, 2005). Irene, whose story of gaining a 3-day extension for their comprehensive exam I described above, had throughout their undergrad and masters arranged accommodations but almost always informally:

...[W]hen I’ve had exams I’ve been able to in previous degrees at other universities say “I have a real issue with the exams.” And I’ve been able to have professors accommodate me through letting me do oral exams instead [...] Cause the process of sitting in a room and writing became more and more stressful. Yeah, and so I’ve been treated for eating disorders before, but not specifically for anxiety around exams. Just like general anxiety. But I hadn’t ever needed to have this taken to the university.

People had usually accommodated around circumstances and taken me for my word. [...] I don't know why there actually- why they require so much documentation? Like is this bureaucratic machine that produces paper trails, right. But like I don't- it's not even clear to me at an administrative level why they need these things.

Teaching staff had found a way, outside the system, to grant Irene access to their learning. Irene points to the current system as perplexing and questions its standards and regulations. Their story highlights how important it is that disabled and mad students coming into higher education have a detailed understanding of this system. With this knowledge, students can start to question the system. Charlie explains how this might work:

I think the solution would be for me to question why things are the way they are. Like why does my program only [last] two years? Why are the courses structured in the way they are? Why isn't there just no deadline? Why isn't there courses you can take in July/August so then it doesn't matter when you take them? Like more flexibility so that it doesn't become ... who is getting what and "be all you need" to push for certain sort of things. Cause I wish there was a world where I wouldn't see myself as having to ask for accommodations and extra help for things, and more time. And having to explain things and then having to worry about things as well. Just having to worry ... Like having to like wonder if I'm going to get extensions? Having to like make sure that like my accommodations are up and renew them every year. I think of all this extra work...

Charlie suggests that disabled and mad students should push back against the normative structures in higher education that regulate who, where, and, when, and how we can disclose and request our different ways of learning are included. Dismantling this structure by demanding explanations for it and working in different ways to subvert (such as getting accommodations without the paperwork) the system is essential. As members of a community, however, this process must be done alongside allies and champions of progressive, equitable change to higher education.

Disabled and mad students want faculty and administrators to play a significant role in moving the conversation about access forward. Charlie describes here what it would mean to

have faculty members as allies in creating new ways of approaching disability and madness in higher education.

But just like changing the way things operate and ... I feel like having profs as allies too. To show- like them being more vocal as well to advocate on your behalf. That way I don't feel like I have to fight the battle myself, or with other students too. Like for my one ... my one friend where she had issues with her practicum. She really rocked the boat in terms of like, she went to like these committees with her faculty and sort of explained her experiences. But like why does she have to have that burden on her? Like that can- that's a lot for her to have. Why isn't it more of a collective process where we're all talking about it and we're all sort of pushing for change? Why does she have to hold all the risk?

When participants did find allies among the teaching staff – those that upload their slides, allow students to record lectures, to use accessible technology in the classroom (i.e., no laptop bans), those that describe images, use large font, contrasting colours, and caption videos, and those who understand the unnecessary hurdles of the disclosure process – they stick with them. Quinn describes what some of these professors are doing and why it's important:

Like I had a professor for a few courses that like ... he knew what was sort of happening [student was in crisis]. And he was like, you know "We can modify assignments for you. Like we can, you know, like waive an assignment if you can't do it." Like he was, you know "You just have to let me know and we can work around this." So that was like really great to have that. ...[H]e generally cares about his students. And it's not like ... like it's not about having the documentation. [...] You know, like if you're struggling I don't want to add to that. [...] But I feel like, I don't know, like he gives his students as much ... – like as many chances to succeed as possible. Which I think is what a teacher should be doing.

Quinn opened up to this professor, and the response was not violent, but caring – and included options for changing the assignments and rearranging parts of the course to ensure Quinn's successful involvement. While such arrangements may not be possible in every discipline or

field of study, surely conversations about how to make classrooms and learning more accessible can take place in every corner of the institution. If disclosure more often led to this type exchange, students would have very little concern about describing their differences to faculty. Administrators would do well to remember this exchange when creating new disclosure policies and regulations, if any, and consider what can be done to ensure a similar response every time a student discloses.

Conclusion

Critical and pedagogically minded instructors are those who are working to dismantle the disclosure process by restructuring curriculum design to reflect more fully who is in their classrooms. The violence of disclosure is not only a contemporary problem in higher education, but rather is a consequence of centuries of exclusion of women, Black, Indigenous, queer and trans people and, of course, disabled and mad people (Dolmage, 2017; Shanouda, forthcoming). Undoing this violence means reconciling with this history. It means moving towards a more universal design of learning – one that is accessible and equity driven.

Those experiencing violence as a consequence of disclosure need to tell someone – have the violence recorded – and call the experience violence. This advice, in many ways, is antithetical to what I've argued throughout this chapter – that disclosing personal information in higher education is harmful. But I am not advising you to disclose disability when telling your story, but to ensure that there are witnesses to your experiences of violence. I've heard, too often, from disabled students, including those in my study, that these violent exchanges were 'part of the deal' of being a disabled or mad student in a highly competitive academic setting. Students must move away from this line of thinking – because violence, of any kind, should never be part of the learning process. Tell your story to someone you trust.

If your disability service officer is supportive, tell them, and ask for your story to be recorded in your file. If you have a good relationship with an instructor, ask them for support, especially if the violence is taking place in their department. Consider visiting the many other places in most universities where students can visit to have these harmful exchanges recorded – equity or human rights offices, offices of the ombudsperson, and even certain student unions or disability-centric student groups can do this work. And finally, and most importantly, share these

stories with other disabled and mad students at your institution and beyond – much like we are doing in writing together this book. In sharing our experiences, we can expect two outcomes: that we realize that these violent experiences are all too common and that the problem isn't our different ways of learning, but that of an ableist and sanist education system; and, that institutions of higher education can no longer ignore the problem that disclosure causes or write it off as anecdotal.

While I am all too aware that disabled and mad students are already working too much to ensure their own access, if possible, do as others have done – and as the participants described above – by attempting to subvert the disclosure process all together. Work with faculty who seem supportive to negotiate ways to include your learning and that allows you to avoid the bureaucracy. This isn't your responsibility, and there is always the looming threat that if granted it may be revoked at any point, and so do this work knowing there are limits and consequences.

Disabled and mad students are not asking for more than what is already guaranteed to them by law and what so much of the scholarship of teaching and learning has indicated is best practice (Price, 2014; Dolmage, 2017). Dismantling the disclosure process is a key step in implementing accessible education because if institutions of higher education don't require disclosure, then the system will have to be accessible from the start. Accessible education – oriented by equity and designed universally – allows students to focus on their learning, and to avoid the violence that disclosure might bring.

References

- Cheuk, F. 2012. Locked Closets and fishbowls: Self-disclosing disabilities. *Critical Disability Discourses/Discours Critiques Dans Le Champ du Handicap*, 4.
- Dolmage, J. 2017. *Academic Ableism: Disability and Higher Education*. Ann Arbor, MI: University of Michigan Press.
- Goode, J. 2007. 'Managing' disability: early experiences of university students with disabilities. *Disability & Society*, 22(1), 35–48.
- Kerschbaum, S.L., Eisenman, L. T. and J.M. Jones, 2017. *Negotiating Disability Disclosure and Higher Education*. Ann Arbor, MI: University of Michigan Press.
- Matthew, N. 2009. Teaching the 'invisible' disabled students in the classroom: disclosure,

- inclusion and the social model of disability. *Teaching in Higher Education*, 14(3), 229-239.
- O’Keeffe, P. 2013. A sense of belonging: improving student retention. *College Student Journal*, 47 (4), p 605-613.
- Olney, M. F., & Brockelman, K. F. 2003. Out of the disability closet: Strategic use of perception management by select university students with disabilities. *Disability & Society*, 18(1), 35-50.
- Price, M. 2014. *Mad at School: Rhetorics of Mental Disability and Academic Life*. Ann Arbor, MI: University of Michigan Press.
- Samuels, E. 2003. My body, my closet: Invisible disability and the limits of coming out discourse. *GLQ: A Journal of Lesbian and Gay Studies*, 9, 223–255.
- Samuels, E. 2014. *Fantasies of Identification: Disability, Gender, Race*. New York, NY: New York University Press.
- Shanouda, F. (forthcoming). The Politics of Passing: Disabled and Mad Students’ Experiences of Disclosure in Higher Education. (Doctoral Dissertation).
- Sierra-Zarella, E. (2005). Adapting and “Passing”: My experiences as a graduate student with multiple invisible disabilities. In L. Ben-Moshe, R. C. Cory, M. Feldbaum, & K. Sagendorf (Eds.) *Building Pedagogical Curb Cuts: Incorporating Disability in the University Classroom and Curriculum* (pp. 139-146). Syracuse: The Graduate School, Syracuse University.
- Reaume, G. 2002. Lunatic to Patient to Person: Nomenclature in Psychiatric History and the Influence of Patients’ Activism in North America. *International Journal of Law and Psychiatry*. 25(4). pp. 405-426.
- Titchkosky, T. 2001. Disability: A Rose by Any Other Name?: “People-First” Language in Canadian Society. *Canadian Review of Sociology/Revue canadienne de sociologie*, 38, pp. 125–140.