# What My Students Taught Me About Disability

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#### Abstract

In spring 2021, I taught a synchronous online course in disability studies, communing with young people struggling with their present and future as educators. The students not only felt empowered to introduce themselves with their preferred pronouns, but they were also empowered to disclose their disabilities. One-third of the students identified as having, or as having had, a disability that significantly impacted their lives: their education, families, and social structures. This article is about what I learned from my students as a result of spontaneous disclosures of their disabilities. As a result, we were brought into conversations about what is important in life in a way I, as an educator, have never witnessed before. Our discussions were filled with their insights, personal stories, and interactions with each other. Excerpts from their dialogue and essays make an important contribution to this paper.

**Keywords:** disability studies, disclosure, access, ableism, higher education

In spring 2021, I was invited to teach a virtual disability studies course at a New York State university where I had been teaching for sixteen years before retiring in 2014. I developed this course over those years, but as a result of the pandemic, it was offered virtually for the first time. Disability studies is a relatively new form of scholarship in the humanities developed and driven by disabled people in the United States, Canada, and the U.K with the common experience of societal oppression. More recently, disability studies in education (DSE) concerns itself with disability as a subject worthy of study, as opposed to special education, which views disability as a deficit to be remediated. Disability studies honors the lived experiences, distinct cultures, and self-representations of disabled people in contrast to pervasive stereotypical representations. Disability is a cultural lifestyle rather than a limitation, a problem, or a void in an individual. Instead, disability studies values the varied and diverse experiences of being and living in the world, including and interconnected with other oppressed groups. With the emergence of the disability rights movement, disabled individuals promote respect and value for their lives, reclaiming disability as a positive identity with the entitlements of the mainstream society.

<sup>1.</sup> In this article I use identity-first and person-first language because both are currently used by people with disabilities. Terminology is important in the representation of disability. Therefore, I consider the use of both forms of identification (disabled people or people with disabilities). I also respect that the American Psychological Association (APA) recommends the latter term (APA, 2010). However, since the disability rights movement, the term disabled people often has been used by disability studies scholars and disabled artists precisely because of the awkwardness and distracting nature of the "person-first" term and the negative connotation of separating disability from the identity of the person.

This article is a loosely-called collaborative autoethnography about what I learned from my students in this synchronous virtual course. Although I am the sole author, the paper is collaborative in the sense that the words of the undergraduate students take a central role. What I learned was the significance of disclosure. Because of several interlocking conditions (e.g., the pandemic and the virtual nature and content of the course), many of the 14 undergraduate students felt confident and, perhaps an urgency, to talk about their lives and identities. Their courage in disclosing their disabilities caused me to re-examine my reasons for withholding my own hidden<sup>2</sup> disabilities from colleagues and students. Those reasons are highlighted later in this article.

This paper is divided into two sections that discuss the meaning and importance of disclosing/not disclosing and the potential risks of both choices. I then describe the course Disability Studies in Art Education. Finally, I present student narratives<sup>3</sup> from the course and weave my own life and positionality throughout these sections. But first, a word about autoethnography.

## **Autoethnography Defined**

Autoethnography is a distinctive style of self-narrative because it engages in social, political, cultural analysis and interpretation. It exists in multiple forms, and is used across the social sciences, including anthropology (Chang, 2008; Denzen, 2006; Reed Danahay, 1997). While the self is present in all these forms, the balance between self and culture varies. Generally, autoethnography serves as a qualitative research methodology that contextualizes self within a cultural frame, or vice versa, weaving culture through an experience and analysis of the self (Bochner & Ellis, 2002; Chang, 2008; Ellis, 2003). As Chang (2008) describes, the choice of emphasis between the research process (graphy), culture (ethno), and self (auto), will determine whether the autoethnography is either emotionally evocative or objective.

Recently, a political, activist model of autoethnography was introduced in the disability community. Tom Couser (1997) coined this new category "autopathography to categorize an emerging literary form that engages the disabled body as a political act" (Wexler & Derby, 2020). A population historically spoken *for* and *about*, now has control over their own stories. Thus, autoethnography, in its many manifestations, is not merely spontaneous self-expression, but an intentional act of claiming one's life (Couser, 2013). Storytelling has power in an ableist world to reframe formulaic narratives about bodymind differences.

Carolyn Ellis (2003) points out that revealing the author's personal life is a potential professional hazard, since autoethnography exposes unappealing characteristics, and therefore invites the reader to judge the text not only on literary merit but also the personal life of the author. The risk is multiplied when disabled academics write autopathography, which has the potential effect of negative career outcomes such as refusal of tenure, or worse. I return to this subject later in this article.

<sup>2.</sup> I use hidden and invisible disabilities interchangeably. However, since writing this paper these terminologies have been questioned. For example, Disability: IN, The Disability Inclusion Blog, prefers *non-apparent disability* because it does not imply a negative connotation. The term *invisible disability*, they suggest, is offensive for some people with disabilities because "It suggests the person is not visible or that you cannot discern that a person has a disability, which is not always true" (https://disabilityin.org/mental-health/non-apparent-disability-vs-hidden-or-invisible-disability-which-term-is-correct/).

<sup>3.</sup> I have been given permission from the students to use their names and words in this paper.

<sup>4.</sup> Ableism is a multi-layered term often defined as disability discrimination and prejudice. It is still in a nascent stage compared with racism, homophobia, and sexism.

While this essay does not fall within autopathography, the students and I reveal our lives to the degree we are comfortable. In our course we discussed the importance of self-examination in order to be authentic educators for our future students. This notion illuminates my choice to use autoethnography. I have found that the benefits of disclosure outweigh disadvantages, such as the ethical preparation of future teachers and curriculum content. For example, Chang (2008) explains that including the self in writing is not a self-centered act, but a way of examining personal experience and, therefore, a more sharpened sense of others, particularly "different" others. Ultimately, the intent of this autoethnography is to promote cultural understanding through the lens of self-examination and personal experience. In my view, the coupling of disability and the pandemic makes essential the disclosure of the author's positionality. Theory omits critical aspects of lived experience from which essential understandings can be communicated.

### My Home

In our ocean-view home I had the privilege to find hope during the pandemic. From my position I peacefully contemplated what might come after, and questioned whether or not there would be an "after," since the possibility we returned to "normal" was doubtful. For people on the margins, "normal" has never been a livable option, and the pandemic has highlighted such inequities. In a second wave, the Delta and Omicron variants invaded what was hoped to be safe spaces in the US, and again the Centers for Disease Control and Prevention (CDC) encouraged citizens to wear masks both indoors and in public places. The anti-vaccination storm continued to weaken and prolong progress towards a future without the deleterious effects of the virus.

I am thus even more aware of my privilege as a white "expatriate" of the United States, who has come to this beautiful country with U.S dollars and built a home with the help of Costa Ricans who, on average, earn only three to four dollars per hour. In voluntary isolation in a small coastal village, suddenly I was communing with young people struggling with their present and future as educators. They have aroused me into contemplation about my contribution as a retired educator. Clearly, my experiences are anecdotal, although I draw on recent scholarship about how students with disabilities were either surviving or prospering in the global pandemic (Berne, Brown, Piepzna-Samarasinha & Heath-Stout, 2020). The course consisted of 14 students: the majority identified as cis-gendered females, one student identified as non-binary, one student identified as male, and one student identified as a cis-gendered male. They not only felt empowered to introduce themselves with their pronouns, but they were also empowered to disclose their disabilities. One-third of the students identified as having had a disability that significantly impacted their lives: their education, families, and social structures. Others had close family members with disabilities. Their trust and candor encouraged me to take the risk to reveal my own multiple invisible disabilities. Self-identification with (invisible) disabilities is important in recognizing that choice exists outside of the classified labels of special education. To be part of the social-symbolic system is the privilege of representing oneself, and thus the significance of "counter-narratives." Through the lens of disability justice and crip theory, disability has meaning and value that resists neoliberal capitalism as "the dominant economic and cultural system" (McRuer, 2006, p. 2), which drives education and specifically special education. Similar to coming out queer or gay as an identity that resists the oppressive medical model, adults with invisible disabilities who were labeled in special education are becoming disabled by choice as an act of liberation and self-actualization. Importantly, as Ellen Samuels (2003) writes, coming out disabled is not a single event, but a decision that is made on a daily basis.

# The Risks of Faculty Disclosure in Academe

Disability has always been constructed as the inverse or opposite of higher Education (Dolmage, 2017, p. 3).

My reluctance in the past as a pre-tenured and tenured professor to disclose my disabilities is manifold. The workload at my state college was well beyond the capacity of most healthy people. The merit system, based on the judgment of one's peers, sustained a culture of unrelenting hard work. As the years went on and resources and funding diminished, the faculty became even more vigilant about who was towing the line and who was "slacking off." Overwork was expected, and those who resisted the culture of overwork were marginalized and maligned. I knew tenure would be endangered if I disclosed my disabilities and sought support and accommodations. Studies have shown both junior and senior faculty seeking accommodations from the university invite disapproval and scorn (Steinberg, Iezzoni, Conill, & Stineman, 2002). Such reprisals from colleagues dampen disabled faculty from pursuing the support they need to teach without restraint. I had not yet found the community of disability studies scholars, and looked upon my lack of energy, focus, and organization skills as my own failings, ones I would need to either compensate for or fix in order to survive.

Jay Dolmage (2017) would argue that my experience is typical given that it is a physical and ideological foundation of the university to keep disability out. He uses the metaphor of "steep steps," a deliberate architectural choice of many universities—an impressive design element but also an imposing one—which literally signals that not all are welcome or desirable. "As a select few stay in, disability is kept out, often quite literally" (p. 3). The U.S. Department of Education revealed in a study in 2004 that the number of tenure-track professors with disabilities remains low, while the majority of disabled professors are adjuncts. The plight of adjunct professors is well-known, such as their need to teach at multiple universities to make a living wage, the lack of healthcare, and a lack of space to meet with students. The burden of these conditions is even greater for adjunct professors with disabilities.

In the article in *Disability Studies Quarterly*, the author who assumed the pseudonym Alice K. Adjunct (2008) wrote, as many disabled authors before and after her have done, despite the passage of the 1990 Americans with Disabilities Act (ADA), disabled faculty struggle with their university's commitment to provide accommodations. Especially for junior faculty, "requests for accommodations may be taken as evidence that they cannot do their jobs as well as able-bodied colleagues. Professors unable to 'make do' without accommodation can face hostile responses from administrators, who see their requests as too expensive or indulgent" (Adjunct, 2008, n.p.). As a result of pervasive stigma, according to Lilah Burke (2021), the assumption of university administrators is that disabled candidates for faculty positions will not perform at the level of non-disabled faculty and will become a burden. Professors with hidden disabilities, therefore, will be reluctant to disclose their disability in the interview process or after they are hired. The lack of "disclosed" faculty with disabilities communicates an unwelcoming message to students with disabilities.

<sup>5.</sup> Reports show that 90% of professors who sue their university under ADA for lack of accommodations have lost their cases (Abram, 2003).

A shift in how disability is perceived is foundational in order to make substantive changes. Disability is often left out of the axis of diversity, 6 "as an identity and an epistemology, a way of being in the world and making meaning in the world" (Dolmage, 2017, p. 42), and therefore is perceived as a problem to be solved by the individual. Like Dolmage, Tanya Titchkosky (2011) describes this problem as a naturalized form of exclusion inherent in the planning, building, and use of social spaces, which are presumed to be inhabited by "the typically functioning normate (male) body (Keifer-Boyd, Wexler, & Kraft, 2020, p. 54). This taken-for-grantedness sets up the conditions for the disabled professor who suddenly shows up as if from a foreign land, requires rethinking and reimagining, and is thus a burden and expense to the university. How can we continue to measure human life and potential in terms of expense, asks Titchkosky (2011)? "More disturbing than the quantification of human life and limb is the social fact that this repetitive routine practice can remain unquestioned and continue to produce the differential value of people" (p. 33). Thinking and reimaging space in service of accessibility for all, the expectation of meeting all forms of bodies and minds on campus, is not a charitable project but a deeply human one. Mia Mingus (2017, 2018) has been shifting the perception of access as solely logistical and spatial towards access founded on justice, relation, connection, and community. In the subsequent section I discuss how Mingus's notions empower faculty, and particularly students, to disclose their disabilities in higher education.

# Student Disclosure, Access Intimacy, and Liberation in Higher Education

Disability disclosure provides a platform to disrupt the hegemonic ableist framework around disability, that is, as an individualistic issue that is easily resolved by technical accommodations (Pearson & Boscovitch, 2019).

While disability resources are almost nonexistent for staff and faculty, higher education has developed disability service offices for students on most campuses (Kerschbaum, Eisenman, & Jones, 2017). Yet insufficient literature exists about disclosure and its ramifications for students in the "often unnoticed, areas of academe where knowledge is produced and power is exchanged" (Price, 2011, p. 60). In the existing research, authors suggest that disclosure is not a single act or event, but an ongoing, dynamic dialogue in a variety of contexts where disability awareness is negotiated (Kerschbaum, Eisenman, & Jones, 2017; Mingus, 2017, 2018; Pearson & Boscovitch, 2019; Price, Salzer, O'Shea, & Kerschbaum, 2017; Samuels, 2003). Nor is disclosure experienced equally given that we come with complicated, intersecting identities, each posing its own risk or cost (Kerschbaum, Eisenman, & Jones, 2017). Holly Pearson and Lisa Boscovitch (2019), who were Ph.D. students with hidden disabilities, wrote a compelling collaborative autoethnography, "Problematizing Disability Disclosure in Higher Education: Shifting Towards a Liberating Humanizing Intersectional Framework." They highlight the personal and professional cost of choos-

<sup>6.</sup> Diversity discourses are replete with contradictions and multiple interpretations. Kerschbaum, Eisenman, and Jones (2017) claim that their complexity is the main challenge to achieving social justice. "And the way in which different people approach diversity is so multivariate and multifaceted that diversity discourses can run the risk of simultaneously saying so much and saying nothing. We don't want diversity to say nothing. It is a principle, a concept that has application to a variety of relationships among people and a variety of challenges that institutions and people face" (pp 3-4).

ing how, when, where, to whom, and if, to disclose. Their critical reflections of their lived experiences in the academy reveal the subtle ableist discourses operating in daily interactions, which impact the retention and achievements of students with disabilities.

As they state in the quotation above, the ultimate purpose of disclosure, in spite of the personal risk of isolation and humiliation, is to work towards non-obligatory access in universities and institutions. They envision the conditions in which empowerment, democracy, and citizenship in higher education replaces the ableist framework of individualism and the technical accommodations required by the ADA. The ADA, while legally providing access and the protection against discrimination, cannot promise that the dispositions and presumptions of faculty and peers will afford an equitable, inclusive, and joyful experience in higher education. Thus, the ableist structure that led to the necessity of federal legal action needs to be re-examined. An anti-ableist framework would relinquish logistics of access founded on burden in favor of relationship and interdependency based on the contribution of disabled people as essential within the rich variation of humanity (Mingus, 2017). Acknowledging disability as an essential and dynamic part of our lives, disrupts the all-too-common perception that disabled people are unexpected guests (Pearson & Boscovitch, 2019).

In this context, disability disclosure is a form of access, one that would require restructuring spaces since few opportunities exist for intimate dialogue in the higher education curriculum. "Disability disclosure could shift the traditional hierarchy between teacher (the depositor) and students (the receivers) towards an environment where all bodies embody value and knowledge, hence structuring an empowering environment" (Pearson & Boscovitch, 2019, n.p.). Opportunities for disclosure within the curriculum invite an examination of underlying power structures in the university. Silence reinforces normalcy while disclosure acts as political resistance.

Pearson and Boscovitch (2019) recount their personal trials as undergraduate students, how they grappled with disclosure versus silence. Pearson arrived at the following realization years after a numbing first attempt at disclosure.

Our genuine and highest learning capacities result as we reveal who we are as individuals. The veil of perceived normalcy dissipates when I continue to disclose who I am. Disability moves freely in and out of my life like a river that has found a home. In disclosing my disability, I break down the walls and assumptions of perception. In revealing, I bring my educational experience of truth to the table. If I stay silent as a researcher and as a scholar, old perceptions become rooted in misperceived constructs of disability, for in silence nothing can change. (n.p.)

In Pearson's narrative, she reveals the injurious effect of disclosing her disability to her professor as an undergraduate in order to receive necessary accommodations. She calls her "threshold moment" the request for her professor's signature, which was met with the following response: "Oh, you are one of those students whose extra time gives you a better chance of earning a better grade in my class" (n.p.). Reading her story was painful. I was not aware of overtly demoralizing student-professor experiences. Yet I am aware that some undergraduates and a few professors tacitly suspect, question, and doubt students with hidden disabilities. Her experience highlights the problem of having the right by law for accommodation and the inability to exercise it with dignity.

Boscovitch's first experiences of disclosure as a young woman were also unproductive. Like Mingus, however, her intersecting identity markers impelled her to demonstrate through her life the impossibility of being compressed into a singular category. Mingus's notion of access intimacy transformed disclosure from degradation into a "tool of liberation" (Mingus, 2017,

para.16) by challenging the hegemonic structures that create an inaccessible world. "The power of access intimacy is that it reorients our approach from one where disabled people are expected to squeeze into able bodied people's world, and instead *calls upon able bodied people to inhabit our world*" (para. 19). Real access requires a shift from individual responsibility to a collective and interdependent existence, acknowledging our dependence on others for our survival, and rebuilding structures in which we challenge oppression collectively. I return to the need for disclosure after describing the disability studies course and how spontaneous disclosure affected our understanding, dialogues, and connections.

#### The Course and The Students

While the able-bodied and able-minded wearied of the pandemic, virtual classrooms afforded disabled students the luxury of participation on an equalized platform. Abled others who joined a changed world temporarily are in a cultural time warp, unaware that disabled people, who comprise the largest minority, have always lived in this space. Virtual classrooms and meetings are not only opportunities to participate, but also a promise for future accessible technology and a decentralization of power and resources. The pandemic has invited professors to be more attentive to and compassionate about the specific situations of individual students, such as depression and anxiety about their futures, let alone deaths in the family.

From my comfortable sunny room, I spoke to students who were struggling through a cold winter in New York's Mid-Hudson Valley, as cases on campus, and campuses around the United States, sored. They struggled under a government that had abandoned them, one of the several reasons my husband and I abandoned the United States. And yet they showed no discernable fear, self-pity, remorse, or defeat. The pandemic brought us to conversations about what is important in life in a way that I, as an educator, never witnessed before. It was in the second week of the semester that I asked students to view *Defiant Lives: The Rise and Triumph of the Disability Rights Movement* by Sarah Barton, a lengthy and potentially disturbing documentary about disability rights. It included vivid footage of the infamous Staten Island Willowbrook State School, a scandalous mental institution revealed by Geraldo Rivera in 1972, which initiated the deinstitutionalization movement in the United States. Their positive interest despite graphic content displayed their forbearance.<sup>7</sup>

The course Disability Studies in Art Education investigates the construction of disability in (Western) society, the invention of normality, and the presumptions about children with disabilities in the art classroom. It advocates for the rejection of medical labels and the individual as the problem in favor of a social-political-relational model that perceives the totality of disability as the person within the environment. Disability studies in education has informed art education (DSAE), and both seek to unmoor disability from special education, as a field of study, like racism and feminism.

Through the lens of the traditional deficit model, disabled people are perceived as abnormal, while non-disabled people are taken for granted as representatives of the universal human,

<sup>7.</sup> In retrospect I realize I should have introduced the documentary with a trigger warning. However, educators debate about the efficacy and benefits of trigger warnings. In 2014, The American Association of University Professors (AAUP) reported that trigger warnings are a threat to academic freedom by discouraging difficult conversations. This point of view, however, is contrary to many disability scholars, such as Margaret Price, whose position is that they are "a matter of *access* rather than *avoidance*," which might require supports in order to engage safely with the material (Kafer, 2016, p. 2).

the prototype from which disabled people depart. The deficit model conceives of disability as a problem to be solved and cured, which is used to justify sorting and separating children in special education based on their differences. We discussed how this misrecognition of disability in society produces ableism in the places in which we live and work, built on invisible decisions made for the "normate" body. Therefore, planning for access is a political act.

Ableism appears in the media, literature, popular culture, and the arts. For example, visual artist Riva Lehrer grew up in the 1960s and 70s when television, movies, art, music, and literature were exploring everything but disability. Lehrer says (2020), "On TV, everyone was beautiful and "normal." People like me were invisible in popular culture, but I felt painfully visible everywhere else" (pp. 185-186). In art school, out of thousands of paintings she studied, she found no portraits of impaired subjects.

Ableism also exists in language. Terms such as *special needs* and *special education* set up barriers to a shared education and socialization between children and youth with disabilities and their nondisabled peers. *Special* and other euphemisms prevent the placement of disability on the same continuum as ability, inhibiting students with disabilities from acknowledging and responding to authentic differences regarding bodyminds and social and cultural understanding. *Differently abled* is another sanitized version of disability. Julia Thompson (2021) wrote in her midterm essay, "Typicals buy the 'differently abled' narrative, so we sell it."

I am at the shallow end of the neurodiversity movement, an Inspiration Porn<sup>8</sup> Star. My momager and I have seamlessly spun my painful, shameful experiences into good PR, brownie points, power-points, and scholarships worth thousands. I talk about my symptoms constantly but I rarely show them, and the soccer moms swoon at my bravery, brilliance, uniqueness. (Thompson, 2021, p. 4)

The notion of "special" was an important topic in the course. With good intentions, special education has sought to cure and normalize students who are different. The illusion of a "normal child" is the root cause of this interest in uniformity, which produces more of the same, the lingering historical factory model of education. It defines who is inside and who is outside this category. Segregation, exclusion, and even integration (which is often called inclusion), move bodies to different spaces that act as forced containers. Integration is the inclusion of disabled bodies only as observers, while excluding disabled perspectives in curriculum content (Moore, 2016).

The source of our discussions in class was drawn from the discussion board, where I asked students to pose three questions for their peers about an assigned text and respond to one question of special interest. We opened the first week with a discussion about David Connor's (2020) provocative article, ""I Don't Like to Be Told that I View a Student with a Deficit Mindset': Why it Matters that Disability Studies in Education Continues to Grow." As a former special education teacher, and later as a retired professor, he offered presentations to in-service educators about the differences between special education and disability studies, emphasizing the limitations of special education's deficit-based understandings of disability. The quote in the title of the article was a statement by one of his participants. Defensiveness, he realized, was an integral part of the work being done in disability studies.

<sup>8.</sup> Stella Young coined the term "Inspiration porn." See her at a TedX Sydney Talk in 2014. (See https://www.youtube.com/watch?v=SxrS7-I sMQ).

When much of the information DSE scholars share is from people with disabilities themselves, and the unintended consequences of special education are presented in critical ways, a form of dissonance occurs. The first engagement with DSE, after all, asks individuals to seriously consider another paradigm of thought. When this happens, all knowledge that has been built upon certain foundations is now called into question. (pp. 28-29)

I hoped the students in my course would embrace the discomfort and anxiety elicited from this discussion as a part of growth, expanding our vision of how disability is conceived in education. The article provoked the most troubling questions in special education: the separate versus inclusive classroom quandary; reaching all students, especially advocating for the self-determination of non-verbal students; and the effects of the medical model in education. In the subsequent section, students respond to questions about course readings through the lens of disability studies and their experiences as the subject or witness to oppressive strategies in special education. Therefore, these responses became a form of disclosure and personal narrative that supported dialogue in class. The following question refers to the medical model, which was answered thoroughly by Sarah Danielson: "How can a search for 'scientific' or biological explanations for disabilities be dangerous? Similarly, how can the search for the 'cause' of disabilities or neurodivergence be counterproductive?"

Sarah Danielson: I think a search for a "scientific" explanation for disability can be dangerous because it looks at disability from a medical model and leads to viewing people with a deficit mindset. The scientific approach is counterproductive and dangerous in education because it creates this line that denotes between "normal" and "other." It leads to an ableist viewpoint where presumptions are made about a student's capability just based on a label. It can create a confined space where students are segregated and not given the same opportunities to achieve. In elementary school I remember disabled students were always in a separate class and I always wondered why we never had classes together. Other students would bully those in the special education classroom because they would say they were "different." I think this separation early on can lead to children forming damaging assumptions about disability and normalcy and lead to stigma around disability. I think what this article [Connor, 2020] was explaining was that even though special education had good intentions, it neglects the socio-cultural aspect and neglects the voice of disabled students, and instead DSE is trying to "challenge deficit-based thinking, 'flipping the script' and seeing disability as normal" (p. 26).

Amanda Monroe responded to the question, "What was your experience with children with disabilities in your schools or jobs? Were they separated or were they more inclusive? If there were inclusion classes, how often were they pulled out for resource instruction or was it push in (meaning the aide goes to the kid)?"

**Amanda Monroe**: I found this question very interesting because I did grow up with an IEP [Individualized Education Plan]. I was a twin born prematurely and was a little behind when it came to reading. I was often separated from my classes to take tests, and often put into different rooms to learn at a different pace. The classes I were in also had secondary teachers to help with any questions I would have. To answer your question, it was a mix of everything. In my opinion, while getting pulled out of class did help with my testing anxiety

it also pushed me back from learning at the same pace as my classmates. I often was bullied growing up. After coming into college and realizing I do not need my accommodations anymore, I find it easier to be more inclusive and be part of a regular class. In class growing up I would often feel as if I was falling behind other students because I was learning at a slower pace. Co-teaching can be beneficial because it allows students to learn the same curriculum. I think that as future educators it is beneficial to take classes regarding disabilities so that we can understand more about how to accommodate certain people. A new age of teaching will help every student to become more understanding of one another.

Towards the end of the semester we discussed hidden disabilities, which invited students to talk about disclosure, the ambiguity of labeling, and the need for care. We watched the documentary *Who Cares About Kelsey?* by Dan Habibe (2013). Kelsey is a white high-school student with multiple disabilities, including attention deficit hyperactive disorder (ADHD) and emotional scars left from homelessness, drug abuse, and self-harm. A team called RENEW was hired by the school to shore up its appalling drop-out rate. Kathy, a member of the team, emerged as a particularly caring professional. Personal narratives in various forms inspire the reader to tell their own story. The following are two responses to questions that surfaced from Kelsey's story.

Danelle Read: Kelsey's story reminded me a lot of my older sister's experience when she was a senior in my high school. She suffered from a lot of mental health problems and missed months of school; the only teacher who seemed to truly care was the **one** school psychologist (in bold because it is insane) who was let go from the school halfway through the school year. I never full on witnessed a teacher say negative words about my sister, but it was extremely frustrating witnessing her teachers favoring and spending a lot of time with certain students who didn't need the extra help and support that she really needed to graduate. Some of those exact teachers were well regarded amongst the school community as "amazing" teachers. It's hard because those teachers, as someone employed by the school, can to a certain extent sway other teachers and administrators into believing that they go above and beyond for their students, but in reality, they just play favorites. The program that the group of teachers came together for in the film seemed like a really great way to hold teachers responsible for their struggling students; I wish my sister had had something similar in my school.

Margo Christie: I think the inspiration we feel from how Kathy, Kelsey's counselor, supported her is because, while it may not be unique, it is rare. It should not be inspirational; it should be commonplace. It seems a shame that we expect counselors and teachers to be these horrible, uncaring people just there for a paycheck or there to force an otherwise unique personality into a predetermined mold. We expect it because it is true. Whether it is the fault of the teacher by giving up on their ideals, the loss of joy for supporting children that got them into education in the first place, or it is a system that requires teachers to shape the square peg into a cylinder so that it could fit in the only hole offered—round. What we as educators can do is to compartmentalize our job into four titles. First, we are hired as *teachers* and so must teach. The etymology of "teach" is to "show, point out, declare, demonstrate," also to give instruction, train, assign, direct, warn, and persuade. This is what is expected of us by the community we work in and by the administration we work under. Then there is *educator*; to educate is to lead, bring forth as in the mind and we do

this among our colleagues, within our schools, looking for the best way to lead the child to a successful end. *Facilitator* is another; this focuses on the capabilities of the child and so we take knowledge and make it easier to grasp, analyze, or synthesize. All three of these positions, facets of our job as a teacher, are focused on us bringing something to the child. We bring them order for the sake of the community, we lead them to correct knowledge for our schools and to prepare them for their future teachers. We also facilitate for them by taking into account the differences in our students, being innovative and imaginative in our approach to informing our students. All three positions are about informing the student. The one "title" that is missing, the one that makes us think, "Oh! Only if we had someone like Kathy the counselor," is *nurturer*. She wasn't trying to change Kelsey's square peg so it could fit into a round hole. Kathy went out of her way to search for that square hole for Kelsey to fit in. To nurture is to look to the needs of the child, not the community, not the school, not our colleagues, but the child. It is what is missing from so much of our education system. What can we do to support all of our students—nurture them!

The following is a well-considered response from Ashlyn, who was diagnosed with ADHD. I asked whether or not ADHD should be considered a mental disorder.

Ashlyn Schuman: In my case with ADHD (inattentive type, formerly known as ADD) and a generalized anxiety disorder, I consider myself to have disabilities. I think that if I don't call it so, I am not giving enough recognition and that it would be unfair to myself. But that is a personal thing. I am not normal, and I feel that I have to acknowledge that in order to not blame myself as much as I used to. Sometimes I feel guilty for calling them disabilities rather than disorders because I feel I am trying to take up the strength of "disability" and I don't want to take that away from others who identify with it, if that makes sense? A lot of people in society do not recognize mental disorders as disabilities either which makes it a bit harder to claim that as my identity. I am not sure that people understand the extent to which ADHD inhibits the things that you do. Everything just feels so overwhelming all the time. It is so hard to get out of bed in the morning or take up personal hygiene. It is so hard to not feel caught up in everything around you, but at the same time everything seems to sit still. It is more than just being fidgety, or out of focus, or disruptive. Those are only symptoms, but at least for me they take a huge mental toll even outside of learning.

- Driving is exhausting; I have to force myself to stay attentive the entire time in order to not be reckless. I got a speeding ticket last semester driving by the school while accidentally daydreaming. People with ADHD are at a higher risk for traffic violations.
- Conversations are difficult. If I am interested, I can only focus on what I want to say rather than wait and listen to what they are saying. Or sometimes I zone out and miss the entire point of a conversation. It is super embarrassing to chime in and say something that has already been said.
- Now when it comes to education, I can't focus on lectures. Everything goes over my head, so I end up reteaching myself. I am always the last to finish a test. It is hard to read- I get bored of the text and think I am reading and next thing I know I am turning the page and realizing I recalled absolutely nothing OR I am fascinated to the point where I distract myself thinking about off topic things. Large texts are overwhelming and so I usually skip through it.

I felt similar to how Kelsey felt during her schooling. I don't know when exactly I started giving up, but it became really apparent in eighth grade when I prioritized certain assignments and ignored others. I was just barely passing my classes. I wish that I had acknowledged my ADHD and gotten a diagnosis sooner. I didn't think the film focused or really described her [Kelsey] ADHD or traumas enough to explain her struggles. The film really only showed a glimpse of it and of her working to achieve her goals.

These conversations, which occurred apart from our synchronized virtual classroom, offered opportunities for students with diverse abilities and proclivities to consider how and if they wanted to reveal their personal struggles. They were written during moments of introspection, given the luxury of time, and they confirmed that disclosure arises through ongoing dialogue. Their narratives also afforded the opportunity for deeper discussion when we returned to our virtual classroom. Being virtual, as we sheltered in place in the familiarity of our homes, also provided the confidence and relaxation needed to fully engage with each other as more than academics.

### **Conclusions**

We offer each other that strength by being vulnerable together, by connecting with each other, by finding ourselves in each other's stories (Bhattacharya, 2016, p. 310).

The many unsolicited self-narratives students so generously wrote on the discussion board encouraged and inspired others to disclose their own stories. Disclosure thus became a more visceral topic as the course went on. In this article, the many examples from both the literature and student narratives attest that "passing" sustains ableist structures, while disclosing resists those structures. Yet silence is often the only option that offers self-worth and opportunity—if only for a limited time—in an ableist world. As many disabled faculty and students explained, however, the price of silence is the loss of self. Julia Thompson (2021) was especially aware of the paradox of the privileges of "passing" with the simultaneous emptying of her identity. She wrote in her midterm paper, "I recognize my privilege and my ableism, yet I struggle to feel seen. I, and others in the movement, reject the idea that we are either abled or disabled. We are both. My reality is simultaneously entertaining and ugly" (p. 5). I hope the students' candor and courage will serve them throughout their careers as educators. They set a precedent for the future of the course, which is to provide trust, comfort, and the conditions for students to grow through intimate dialogue.

### References

Abram, S. (2003). The Americans with disabilities act in higher education: The plight of disabled faculty. *Journal of Law and Education 32*(1), 1-19.

Adjunct, A.K. (2008). The revolving ramp: Disability and the new adjunct economy. *Disability Studies Quarterly*, 28(3).

Barton, S. (Director). (2017). Defiant lives: The rise and triumph of the disability rights movement [Film]. Victoria, Australia.

- Berne, P., Brown, L.X.Z., Piepzna-Samarasinha, L., Heath-Stout, A. (Hosts). (2020, April 14). *Organizing in a pandemic: Disability justice wisdom*. [61] [Audio podcast episode]. Irresistible, https://docs.google.com/document/d/1mCfsftzqOZbQk3JaD10q6CPYM-RCySYl4i7nH752RLbg/edit
- Bhattacharya, K. (Bhattacharya, K. (2016). The vulnerable academic: Personal narratives and strategic de/colonizing of academic structures. *Qualitative Inquiry*, 22(5), 309–321.
- Bochner, A.P. & Ellis, C. (Eds.). (2002). *Ethnographically speaking: Autoethnography, literature and aesthetics*. Alta Mira Press.
- Bolt, D. (2015). Disability, avoidance and the academy: Challenging resistance. Routledge.
- Burke, L. (2021, May 12). A difficult pathway. Inside Higher Ed.
- Chang, H. (2008). Autoethnography as method. Walnut Creek.
- Connor, D. (2020). "I don't like to be told that I view a student with a deficit mindset": Why it matters that disability studies in education continues to grow. *Canadian Journal of Disability Studies* 9(5), 19-41.
- Couser, T. (1997). *Recovering bodies: Illness, disability, and life writing*. University of Wisconsin Press.
- Couser, T. (2013). Disability, life narrative, and representation. In L. Davis (Ed.). *The Disability Studies Reader*. pp. 456-9. Routledge.
- Denzin, N. K. (2006). Sociological methods: A sourcebook. (5th ed.). Aldine Transaction.
- Disability: IN. (n.d.) "Non-apparent disability" vs. "hidden" or "invisible disability"—which term is correct? https://disabilityin.org/mental-health/non-apparent-disability-vs-hidden-or-invisible-disability-which-term-is-correct/
- Dolmage, J. (2017). *Academic ableism: Disability and higher education*. University of Michigan Press.
- Ellis, C. (2003). *The ethnographic I: A methodological novel about ethnography*. Alta Mira Press. Habibe, D. (Director) (2013). *Who cares about Kelsey?* [Motion picture]. U.S. DH. Photography
- and Institute on Disability at the University of New Hampshire.

  Kafer, A. (2016). Un/Safe disclosures: Scenes of disability and trauma. *Journal of Literary & Cultural Disability Studies* 10(1), 1-20.
- Keifer-Boyd, K, Wexler, A. & Kraft, M. (2020). "Are you sure you belong here? In A. Wexler & J. Derby (Eds.). *Contemporary art and disability studies*. Routledge.
- Kerschbaum, S. L., Eisenman, L. T., & Jones, J. M. (2017). *Negotiating disability: Disclosure and higher education*. University of Michigan Press.
- Lerher, R. (2020). Presence and absence: The Paradox of Disability in Portraiture. In A. Wexler and J. Derby (Eds.)." *Contemporary art and disability studies*. Routledge.
- Mingus, M. (2017, April 12). Access intimacy, interdependence and disability justice [Blog post]. https://leavingevidence.wordpress.com/2017/04/12/access-intimacyinterdependence-and-disability-justice/
- Mingus, M. (2018, November 3). "Disability justice" is simply another term for love. [Blog post]. https://leavingevidence.wordpress.com/2018/11/03/disability-justice-is-simply-another-term-for-love/
- Moore, S. (2016). One without the other: Stories of unity through diversity and inclusion. Portage & Main Press.

- Pearson, H. & Boscovitch, L. (2019). Problematizing disability disclosure in higher education: Shifting towards a liberating humanizing intersectional framework. *Disability Studies Quarterly* 39(1).
- Price, M. (2011). *Mad at school: Rhetorics of mental disability and academic life*. University of Michigan Press.
- Price, M. Salzer, M., O'Shea, & Kerschbaum (2017). Disclosure of mental disability by college and university faculty: The negotiation of supports, accommodations, and barriers. *Disability Studies Quarterly*, 37(2).
- Reed Danahay (Ed.). (1997). Auto/ethnography: Rewriting the self and the social. Routledge.
- Samuels, E. J. (2003). My body, my closet: Invisible disability and the limits of coming-out discourse. *GLQ*: A Journal of Lesbian and Gay Studies 1, 233-255.
- Steinberg, A.G., Iezzoni, L.I, Conill, A., & Stineman, M. (2002). Reasonable accommodations for medical faculty with disabilities. *Journal of the American Medical Association*, 288 (24), 3147-49.
- Titchkosky, T. (2011). *The question of access: Disability, space, and meaning.* University of Toronto Press.
- U.S. Department of Education, National Center for Educational Statistics. (2016). *Digest of Education Statistics*. https://nces.ed.gov/fastfacts/display.asp?id=60
- Wexler, A. & Derby, J. (Eds.). (2020). Contemporary art and disability studies. Routledge.