The Impact of Disbelief: On Being a Library Employee with a Disability

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Abstract

As a library employee with a hidden disability (post-traumatic stress disorder [PTSD]), just going through the accommodation process is difficult. The process is invasive and includes an in-depth interview with a disability specialist who knows nothing about you. The process also requires a letter from a care provider detailing both the accommodation and why it is necessary. In order to get an accommodation, the person must first be diagnosed by a medical professional or a psychiatrist, which is often expensive and time-consuming to obtain. The process is made more difficult and painful when supervisors and administrators do not recognize the validity of the condition for which the accommodation is needed. This paper explores the accommodation process, its impact on the employee, and the politics and psychology of disbelief and suspicion surrounding disability accommodation. Through the lens of personal experience and reflection, I will explore how the library, while a place of learning and advocacy for knowledge, can also be a place of ableist views that limit the abilities and potential of employees with disabilities. I will also provide guidelines for combating ableism in the library workplace.

Introduction

There is little data about the number of library employees who have disabilities and even less data on how many of those employees have accommodations. Heather Hill (2013, 139, 141), in her analysis of library literature for themes around disability, points out that the literature, at least up to 2013, focused on accessibility of electronic resources, and that

the bulk of articles talk about people with disabilities but don't typically involve people with disabilities in accessibility/disability research. This disparity of inclusion makes it seem as if people with disabilities are few in number, but this is not so. The World Health Organization (2018) states that about 15 percent of the global population has a disability. According to the US Census, in 2010, 18.7 percent of the US population had a disability (Brault 2012, 4). In a study comprised of faculty and staff at a large Midwestern university, researchers found that 15 percent of respondents had a disability (Shigaki et al. 2012, 563). While people with disabilities make up a significant portion of the population, their needs are often misunderstood, and employers have lagged far behind on not only compliance with the law but also creating inclusive and welcoming environments, as evidenced by the increasing number of Equal Employment Opportunity Commission complaints, with 26,838 complaints in FY2017 alone (EEOC, n.d.). People with physical or visible disabilities generally have an easier accommodation process than people who have hidden disabilities, especially mental health ones. McDowell and Fossey (2015, 201), in their scoping review of accommodations for people with mental disabilities, discuss the unmet accommodation needs of this population and how it is most probably attributable to a combination of factors, including a lack of knowledge on both the employee's and employer's parts and stigma that leads many people with mental health disabilities to hide them rather than reveal them.

If they are able, many people with disabilities choose not to reveal their disabilities at work and instead struggle to function as best as they can. Goldberg, Killeen, and O'Day (2005, 484–87), in their article on people with mental disabilities and the decision to disclose, conclude that people with mental disabilities do not disclose because of stigma, fear of being mistreated, and retaliation by the employer. However, the decision to disclose brings access to accommodations that can have a major impact on an employee's working and personal life. Employees who get workplace accommodations also generally have higher rates of job satisfaction (Balser and Harris 2008, 25). However, many universities do not put sufficient resources into supporting employees with disabilities. Dolmage (2017, 176) argues that disability in the academy is far more prevalent than many people realize and that the academy not only undervalues the work of people with disabilities but consistently undersupports them as well: "In the United States, the average operating budget of the entire disability services is about $250,000. That could pay for one-eighth of a football coach. . . . This lack of investment tells the rest of the university that disability doesn't matter." Where money, time, and attention are placed matters significantly in so far as signaling what is important. The lack of investment, discussion, and time spent on supporting academics with disabilities is a clear message that academics with disabilities aren't valued.

This runs contrary to the current rhetoric of diversity and inclusion that is rampant at institutions of higher education.

For instance, at the University of Illinois at Urbana-Champaign, the Disability Resources and Educational Services (DRES) unit that assists students with disabilities is generally considered to be quite extensive and better than most other universities of comparable size. DRES has a staff of thirty-eight people and served 2,355 students in the 2017–2018 school year (Collins 2018) out of an undergraduate enrollment of 39,004, for a total of about 6 percent of the undergraduate student population. Put another way, there is one person working at DRES for every 1,026 students. However, the same services for faculty and staff are not nearly at the same level. The Office of Diversity, Equity and Access (ODEA) fulfills a variety of roles, including disability accommodations for faculty and staff. ODEA has a staff of twelve people, of which only two are designated as accommodation specialists. These two people support, in theory, 10,845 faculty and staff (University of Illinois 2018), or, for every one accommodation specialist, there are 5,422 faculty and staff. It is unknown how many faculty and staff ODEA assisted with accommodations last year. As recently as 2016, there was only one person working part-time on faculty and staff accommodations. While the situation at the university has since marginally improved for faculty and staff—with the hiring of a full-time accommodation specialist and modification of the duties of the part-time specialist so they work on accommodations full-time—ODEA is still understaffed and underfunded. On orders of magnitude, the disparity in accommodation support between students and faculty and staff at the University of Illinois at Urbana-Champaign is staggering.

Funding and personnel staffing issues aside, the very real crisis for employees in higher education with disabilities is multifaceted and systemic. Problems range from inaccessible buildings and classrooms to subtly ableist discrimination during routine processes that have rarely been evaluated for accessibility, such as room configurations where meetings are held or expectations for when and how work is accomplished. Kerschbaum et al. (2017, 312) examine the disclosure process to get an accommodation for faculty with mental disabilities in higher education, including the systemic issues that faculty with mental disabilities face. They sum up the storm of emotions that a faculty member with a mental disability faces when they start the accommodation process, which includes disclosure of their disability: "When a disability is not easily identified or named . . . or when needed accommodations are not already available as options on a checklist, negotiating accommodations can feel scary, be risky, or altogether fail to meet faculty members' needs." It is in this context of disclosure and accommodation that this article gives a brief snapshot of the accommodation process, discusses the discrimination that employees with disabilities face, and provides guidelines for working to resolve these issues.

ADA AND THE ACCOMMODATION PROCESS

The Americans with Disabilities Act of 1990 (ADA) makes provisions for accommodations for people with disabilities. Disability is broadly defined as generally any kind of physical, mental, cognitive, or sensory impairment that impacts activities of daily living. Accommodations more generally are adjustments made to the working or learning environment in order to allow the person with a disability to work at the same level as their nondisabled colleagues. Although this sounds straightforward, there are caveats within the law that allow many employers to circumvent the accommodations that people with disabilities need. One of the caveats relates to the cost of the accommodation. Employers can ask for an exemption if the accommodation represents an undue financial hardship. The law also has subjective terms such as "reasonable accommodation" and "essential job function" that are often hotly contested by employers because the terms are not well defined. What the employee believes is reasonable for their accommodation and what the employer thinks is reasonable for the accommodation are often different. One reason for this is disbelief on the part of the employer in regards to what the employee needs and whether or not the employee has a real disability, especially if the disability is a hidden or invisible one. The level of employer disbelief seems to rise exponentially with the degree to which the disability is hidden. For instance, if a person has a mental disability such as PTSD, there are generally little to no outward signs that the employee has a disability. The lack of outward or visible signs of disability unfortunately all too often lead to a belief that the employee is lying about having a disability or is attention seeking. If the employee has a visible disability, such as using a wheelchair or missing a limb, accommodations are often granted immediately and without contest. However, if the disability is a hidden one, such as in the case of mental-health disorders, many sensory conditions, chronic pain conditions, sleep disorders, neurodiversity, etc., there is typically more pushback and a mistaken belief that the employee is "faking it" to either get out of doing work or to get special privileges (Santuzzi et al. 2014, 208). Pilling (2013), in his work on the nature of identity and mental disabilities, referred to as "madness" by him, discusses the intersection of having a hidden disability, disclosure and accommodation in the workplace, and identity. He examines how invisibility is becoming an area of concern within disability studies. Within his research study where he interviewed thirty-six people in Canada with hidden mental disabilities, he remarks that there is a connection between the visible nature of a disability and the belief by an employer as to whether or not the person needed an accommodation or even had the disability that they were claiming to have: "Given the lack of visual signs to make madness immediately 'readable' off the body, participants in my study were commonly assumed not to be mad."

Regardless of the level of pushback, the accommodation process gener-

ally follows the same steps in most organizations. These steps may or may not be sequential because each situation is unique. Generally, however, the process looks something like this:

- Employee goes to their supervisor and/or human resources and asks for an accommodation.
- In larger institutions, the employee might be sent to an accommodation specialist. In smaller institutions, the accommodation process might be negotiated between human resources, the supervisor, and the employee.
- The employee provides documentation of their disability. Documentation is typically from a health-service provider. For physical disabilities, this is usually a medical doctor. For mental-health disabilities, this could be a therapist. Typically, the letter will discuss what disability the employee has, what symptoms they are experiencing, and recommendations for accommodations.
- There is a discussion, typically without the employee, regarding what accommodations the library can provide.
- An offer is made to the employee, and the employee tries out what has been offered. After trying out the accommodation, the employee provides feedback. If the accommodation is not working for the employee, another accommodation is discussed and tried out. The accommodation process is iterative, so if the accommodations needed are particularly complex or extensive, the process might take weeks or months.
- Once the accommodations have been worked out to everyone's satisfaction, there is usually a prolonged pilot period and then a follow-up meeting weeks or months later to see if the accommodations are still working as intended. The follow-up meeting is also an opportunity to make adjustments if needed.

The accommodation process looks pretty straightforward, but there can be many barriers during the process that can lead to dissatisfaction for everyone involved. Barriers can include stereotyping, stigma, miscommunication, ableism, and misunderstanding, to name a few. People with hidden or invisible disabilities often have the option of continuing to hide them and struggle on as best as they can. Santuzzi et al. (2014, 206, 212) explore in depth the issues that people with invisible disabilities face at work. They examine the topic from multiple sides, including policy, health, and social aspects. They also explore the negative impacts of disclosing a hidden disability in order to get an accommodation at work, which include disbelief in the legitimacy of the disability, stigmatization, social exclusion, prejudicial treatment, and retaliation. In short, a person with a hidden disability could potentially face negative consequences regardless of whether they disclose, which makes the decision to disclose or conceal deeply personal and fraught with uncertainty.

Disability and Disbelief

There are several components surrounding how employers and fellow employees interact with a person with a disability. Stigma, harassment, ableism, and an institutional culture that values overwork all contribute to whether or not a person with a disability will disclose in order to get the accommodations that they need. Stigma is at the root of much of the discrimination that people with disabilities face. Erving Goffman (1963), the pioneering researcher in this area, argues that stigma is a result of the things that set people apart and that the rest of society then punishes the person for. At the time that he was writing his seminal work in the 1960s, he used examples like homosexuality, physical disabilities, radical political views, and extreme personality traits such as being overly dominant.

What is the impact of stigma?

> Stigma experiences have caused hurt, anger, discouragement, and lasting damage to self-esteem. They have led many . . . to conceal their psychiatric histories from others, to withhold information on applications for jobs and licenses, and then to be burdened with chronic fear of disclosure in addition to pain and stress of their illnesses. Experiences have led many . . . to maintain a secrecy that not only is uncomfortable but also may contribute to the very symptoms—anxiety, depression, paranoia—from which they are struggling to recover. (Wahl 1999, 475–76).

While Wahl is specifically discussing mental-health disorders, the impact of stigma for people with other types of disabilities is substantial. Many people with disabilities go out of their way to conceal their disabilities and "pass" as able-bodied. However, the impact of "passing" should not be dismissed as minor, and there are often long-ranging consequences in terms of productivity, employee morale and satisfaction, and physical and mental health. In regards to the decision to continue concealing an invisible disability, negative health impacts include "negative psychological states (depression, anxiety, low self-esteem, and distress) and engag[ing] in risky health behaviors if they have negative expectations about others' reactions to the identity. Consequently, individuals with invisible stigmatized conditions are expected to experience more physical illness, severity of symptoms, and/or lower quality of life" (Santuzzi et al. 2014, 206). In my own experience, while I was waiting for my accommodation (a process that took nine months) and ineffectively de facto concealing my PTSD, the impact of the wait and concealment was resoundingly negative. I dreaded going to work every day because I was constantly triggered by my environment, my anxiety was at an all-time high, I was on extra medication for the anxiety attacks I was suffering, and I had suicidal ideation. Luckily for me, I had a very robust support network in the form of friends and my therapist. I also had a "toolbox" of strategies that I used to keep me going, which included dialectical behavior therapy, video games (escapism), crafting (self-soothing behavior that helped calm me or keep me

calm), my cats (comfort and emotional support), medication, hot showers (physical sensation that interrupts cyclical thinking), and so forth. Still, the wait took a tremendous toll on me: my house cleaning and personal care suffered as I became more anxious and depressed, I became angry more quickly, and my sarcastic sense of humor reached an all-time high, which alienated others. My filters for what was socially appropriate eroded; for example, I would answer the question "How are you?" with "Not dead yet." In short, it was not the best time of my life.

The resistance to accommodations by employers stems from a variety of conditions, including culture of the place, worries about costs, and attitudes by people in power (Williams-Whitt 2007, 407–8). These misperceptions often stem from stigma and misinformation as well as apocryphal stories of a single employee who at one time abused the system in some way. As a result, there is a feeling that providing accommodations is somehow unfair, which then stigmatizes the employee with an accommodation further. Robert and Harlan (2006) have studied discrimination toward people with disabilities in large organizations. One of their findings specifically examines the marginalization and stigmatization that employees face because of their disabilities and accommodations and includes the social consequences of disability in the workplace: "Even those workers with disabilities who reported having 'good,' 'cordial,' or even 'friendly' relationships with coworkers and supervisors generally had a problematic relationship with one or two of them or were 'left out' of various social and support networks. These individuals typically reacted by withdrawing or giving up. . . . Over time, such individuals often stopped trying to make friends or to find social support in the work place" (609).

In my case, there was absolutely cultural pushback. My recommended accommodation was an enclosed office, but there weren't any within my department that were available. There were offices on the fourth floor, away from my department, that were empty and had been empty for years, and yet to get one of those offices took nine months and hiring a lawyer. When I finally did get my accommodation, there was an announcement made to my department that disclosed my disability without my consent, an act of aggressive retaliation for seeking out what I needed. As time has passed, even after getting my accommodation, I have felt excluded and singled out. In part due to the contentious accommodations process and nonconsensual disclosure of my disability status, I have struggled to survive in a hostile work environment. Faced with an extremely long wait for an accommodation and then aggressive retaliation, it's not surprising that people with disabilities try not to ask for accommodations or try to "pass" as able-bodied. If I had been able to continue to work in my preaccommodation setting, I would have. However, the impact on my mental and physical health of being in the open-air office that I was in was too overwhelming. I was approaching a breaking point when I started the ac-

commodation process, and the long wait for my accommodation caused a great deal of mental harm, which I am still healing from a year later.

Invisible disabilities are often the object of more misperceptions than physical ones. Brown and Leigh (2018, 987) discuss the ableism that is widespread within academia and point out that people with hidden disabilities are especially targeted for being disbelieved: "Invisible, less known or contested conditions are dismissed as a fabrication, malingering and an act of a fundamentally lazy or overwhelmed worker seeking validation." Their assessment is predicated on the assumption by society that all people are able-bodied and neurotypical. This is further supported by Williams-Whitt (2007), whose work focuses on accommodations and the impact of the process on employees, especially when a workers union is involved: "Accommodated employees sensed that they were unwelcome. . . . Reluctance and bias were heightened where managers questioned the employee's credibility or the legitimacy of the illness." While there has been no direct questioning of my disability, the indirect questioning and passive-aggressive and aggressive behavior toward me has been palpable. Examples include but are not limited to having a note taker present at meetings where no note taker was ever present before or for anyone else (a note taker is not part of my accommodation), not being invited to social events, silent erosion of some job responsibilities, conversations ceasing when I enter a room, and being bullied by colleagues, including being told that no one liked me.

When people with disabilities disclose, it is often after an extensive risk/benefit analysis. Again, Brown and Leigh (2018) discuss the double bind of disability within the academy. While the academy says it accepts difference and disability, the reality and expectation is that workers within the academy must conform, and not doing so is to invite censure and stigma. "Disclosure is understood in connection with 'disclosing' something that people are ashamed of, keep secret and then feel obliged to open up about. If we reject ableism, then we should be comfortable with illness or disability, and so should not feel the need to 'disclose'" (986). Breaking that conformity of ableism by revealing disability and asking for accommodations represents an aggressive sundering of the silent pact of conformity, especially when, in my case, one is in a tenuous position of being tenure-track and not yet tenured. Disclosure is often fraught with uncertainty in terms of how well both it and any subsequent requests for accommodations will be accepted as well as the impact disclosure will have on relationships, the work environment, and in my case, whether or not it would affect my tenure case.

It is much more difficult for employees in workplaces with toxic or dysfunctional cultures to disclose because the culture itself is so negative. Beretz (2003) examines what it means to have a hidden disability and an academic career. Specifically, Beretz explores what the cycle of illness does

to the level of production that an academic can accomplish and how the academy punishes academics with disabilities not only for not keeping up with able-bodied colleagues but also for having a disability in the first place. As she explains it, "American culture has a profound discomfort with disease and disability. We equate health with ability and power. . . . We tend to blame people for their disabilities. We see illness as a lack of self-control; chronic illness as failure to 'shape up.' People fighting illness are considered weak in spirit and mind, as well as in body" (52). In this kind of cultural environment where there are very real risks involved in speaking up and out about one's disability, to do so is an act undertaken usually in desperation and as a last resort. In my own case, it was absolutely an act of desperate need. My disability is post-traumatic stress disorder. I have hypervigilance and hearing hyperacuity. I am acutely aware of my surroundings at all times. After having struggled in an open-air office for about two years where there was no auditory privacy, my ability to concentrate was deeply eroded by the constant need to be aware of everything around me. This ranged from the librarian one cube over eating their lunch to the students working on computers on the other side of my cube wall to the employee across the room continuously chatting on their phone. The constant state of hypervigilance was taking a toll on my mental and physical health as well as on my social interactions. After spending so much energy every day trying to survive in the open-air cube, there was no energy left over to be social, explore the town I had just moved to, or to make new friends and enjoy hobbies. It was all I could do to survive, and surviving was all I was doing. I realized after much soul searching and reflection that I absolutely needed to change my work situation if I was to continue to survive and, more importantly, thrive.

Speaking up and asking for accommodations is often difficult because in conjunction with the issues discussed above, there are also issues with misinformation and a complete lack of information that employees need to contend with. O'Neill and Urquhart (2011) studied the perceptions and understanding of library managers in regards to when employees asked for accommodations. They found that there were several issues around perceptions of accommodation, including that "library managers' current 'awareness' is passive and does not wholly translate into practical compliance. In practical terms, it means library staff with disabilities wishing to present a request for accommodation to a library manager will be confronted by an extra burden, the lack of precedent and accepted practice" (252). This was absolutely true in my experience. While the library had done accommodations for people before, my impression was that it was for people with physical disabilities more often than mental ones. This means that the burden of education falls on the employee with a disability and not on the supervisor or human resources department. Fortunately, many supervisors and human resources departments want to improve and

are willing to learn the basics of accommodation. There is a lack of understanding on the part of managers around people with disabilities, visible or hidden, but generally, managers are willing to learn about accommodations and how to work with their employees with disabilities. "The overall picture presented in relation to accommodation of employees with less visible disabilities is one of a lack of specific knowledge on the part of library managers of the needs of, and accommodations for, the staff with the less visible disability but a willingness to consider ways of accommodating them where their disability would not place them at a disadvantage" (O'Neill and Urquhart 2011, 251). While I know that my employer looked at the Job Accommodation Network database, the back and forth between us about how to accommodate my needs for silence and safety indicated that they didn't really understand my disability. I once compared the feeling of being in my open-air office during the accommodation process to being a battle-scarred mouse that had been brutally played with by cats for years, and that being in the open-air office meant the smell of cat was always present and therefore always terrifying. I don't know if the analogy helped, but I would like to think it did in terms of building not only understanding but also empathy.

Positive experience with accommodations often brings greater overall employee improvements. Von Schrader, Malzer, and Bruyère (2014) conducted a study on why and when employees disclose their disabilities and the effect that such disclosure had on them. While they recount negative experiences, like many articles do, they also examine the positive experiences of employees with disabilities who have accommodations, such as "improved employee productivity, attendance, attitudes and coworker interaction, as well as lower stress levels, improved coworker attitudes and increased overall organizational morale. . . . Employees who perceive that their workplace has an inclusive climate feel higher levels of psychological empowerment on the job and higher levels of organizational support" (15). Once I got my accommodation, the relief I felt was palpable. My stratospherically high stress levels immediately went down and, while there was a period of adjustment, I felt like I was finally safe and my productivity skyrocketed as a result. As the months of being in a safe work space continued, my anxiety and hypervigilance eased slowly from hair-triggered sensitivity to a more normal-for-me level. As a result of this lessening of my stress levels, my good humor, tolerance of microaggressions, and easygoing nature reasserted itself.

Negative accommodation experiences bring the opposite for employees who have gone through the accommodations process. Balser and Harris (2008) explored the satisfaction of employees who received accommodations and found that while accommodations experiences that were inclusive of the employee were viewed positively by the employee, the opposite was true when the employee was not part of the accommoda-

tion process. They explain that "employees that have negative reactions to the accommodation may be more likely to experience a decline in organizational commitment, perceive low organizational support, leave the organization, or perceive that discrimination has occurred, all of which can affect not only the employee but the organization as well" (15). On the other hand, having had an extremely long accommodation process, as well as having had to hire a disability lawyer, took a negative toll on me. From my perspective, I had struggled and suffered needlessly for months. Because of the long wait, my interactions with people and my work productivity absolutely suffered as I became more agitated, short tempered, and anxiety ridden.

A Framework for Inclusivity and Acceptance of Employees with Disabilities

Develop a Culture of Equity

While it seems that everyone is talking about diversity and inclusion these days, they often are focusing on race, gender, and ethnicity. These topics absolutely should be discussed, and disability definitely intersects with them. However, the discussion around diversity and inclusion far too often leaves out discussion of disability as a minority issue in its own right. Include disability and accessibility from the onset of any discussion, initiative, or change. Inclusion is as much about mindset as it is about making sure that there are interpreters, seating, safe spaces, etc., for people with disabilities. It is about seeing the world from multiple perspectives as you move through it.

Use Universal Design

Universal Design is about making sure that a service, an object, a pathway, pretty much anything is usable by everyone, at every stage of life, from cradle to grave (National Disability Authority, Centre for Excellence in Universal Design, n.d.). Universal Design takes into account differing abilities. For instance, instead of door knobs on doors, which can be hard to grasp if you have low or no hand strength, think of using low pressure door handles that allow for ease of movement.

Educate All Employees

Very few people are generally self-motivated to be reflective and to push their boundaries, especially if they are uncomfortable with a topic. Having an educational program that focuses on microaggressions, implicit bias, and other types of discrimination will go a long way toward reducing conflicts and misunderstandings. When there is a culture of tolerance and open discussion about issues and miscommunication, there is less likely to be high staff turnover and other problems.

Model Appropriate Behaviors
Managers should be held to the highest ethical standards and should model behaviors that support inclusivity, understanding, and tolerance. When managers say they want equity and equality and then do everything in their power to not be inclusive and equal, this sends a powerful message to employees about where the priorities really are and what's actually important.

CONCLUSION

Accommodation, from whichever angle you approach it, is not an easy thing. Done right, it leads to happier and more dedicated employees who work more efficiently. Done wrong, accommodations create resentment, a sense of betrayal, and a devaluing of the self for the person who is asking for them. While the law is clear that accommodations must be offered to people who ask for them, the law does not stipulate that employers have to understand, educate, or embrace the person with a disability, and that is the crux of the issue. When employers don't support their employees with disabilities well, it sends a clear message that those employees don't matter. While diversity, inclusion, and equity are written into many strategic plans, guiding principles, and mission statements, there is a very definite difference between saying it and acting on these principles.

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