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Essays and Opinion Pieces

Facing New Challenges: Recovering from Bell's Palsy and Shifting to a Flexible Work Paradigm

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ABSTRACT

In this essay, I reflect on my experience being diagnosed with Bell's palsy while in a new job, and how this diagnosis frames my appreciation and advocacy for flexible work arrangements in libraries. As we move out of the height of the pandemic, offering flexible work arrangements is one way in which libraries can cultivate a culture of care that prioritizes the health and wellbeing of all employees. I reflect on how my sudden diagnosis impacted my work and became a catalyst for critiquing my own expectations for my productivity in a remote work environment, and how libraries can begin to unravel these norms on an institutional level.

KEYWORDS

Flexible work arrangements, culture of care, compassionate leadership, disability

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Following the height of the pandemic, libraries are positioned to cultivate a culture of care and compassion and challenge problematic, often unspoken, norms around workplace productivity. A culture of care prioritizes employee health and wellbeing, and offering flexible work arrangements is one simple way to foster support and understanding among all employees, even those who may not currently need an accommodation for a physical or mental condition. The unexpected can and likely will happen, and I came to appreciate this, and the benefit of working remotely, following a sudden diagnosis of Bell's palsy, which paralyzed the left side of my face. In this essay, I reflect on my experience with my diagnosis and address the widespread need not only for flexible work arrangements across libraries, but also the need for respect and autonomy for those who use them.

An Unexpected Diagnosis

Over the winter break of 2022, I was enjoying time off for the holidays by visiting with family and friends, excited to share news about the new job I had started just a few months prior. I was finding my new role and work environment both rewarding and fulfilling. I liked my new supervisor and colleagues, and I was excited to go to work every day—or, in some cases, work from home, as I was enjoying more opportunities to work remotely than in my previous job.

This was not news to my parents, since I visited with them periodically in the months prior to my visit with them on December 29. It was an otherwise typical day, but I had been feeling strange all morning. At breakfast, I noticed a dramatic change in my sense of taste. It felt almost like there was a film covering my tongue, dulling the taste of an otherwise flavorful breakfast. After a negative COVID test, I dismissed my concerns and started getting ready to leave. Nevertheless, I could not help but notice other strange things happening: my cheek felt slightly numb, and I realized when I brushed my teeth that my mouth was favoring one side. When I blinked, my left eye was slower to close, like it was in slow motion, and it was twitching relentlessly. Odd though it was, I brushed all these symptoms off, thinking that maybe I was just tired. By the time I returned home after my visit, my symptoms had escalated; I had an intense and unusual headache, with pain radiating from behind my left ear down my jawline, and I realized I was losing control of the left side of my face.

The next day, I was diagnosed with Bell's palsy, an idiopathic condition resulting from inflammation of the seventh cranial nerve that controls the facial muscles. The inflammation causes the nerve to swell and subsequently get pinched by the narrow canal it runs through in the skull, resulting in muscle weakness or paralysis in the face on one side (though in some cases, both sides are impacted). The cause is unknown, and there is no effective treatment. After seeing my primary care physician, a neurologist, an ophthalmologist, and a physical therapist, and receiving several bouts of blood tests, X-rays, and MRIs, the resounding conclusion was that the only treatment for my condition was time. The doctors recommended all of the tests to rule out any potentially identifiable (and thus more problematic) cause, but it did not change the fact that I would have to learn how to live with this new condition for a while. I was told it could take up to six months to fully recover, if not longer. Though uncommon, some patients never fully recover from the condition, suffering permanent paralysis. Others experience residual effects for years.

The winter break gave me some time to process the sudden and drastic change I experienced, but it still was not easy at first. Losing control of one side of your face impacts everything. I had to learn how to eat and drink when I could not fully close my mouth. I could not fully close my left eye either, so I had to tape it shut at night and use eye drops every hour during the day to keep it hydrated and healthy. Even with those measures, my vision soon became blurry and unpredictable. My sense of taste took several weeks to return to normal, and for the first few months I was extremely sensitive to bright light and loud sounds. Talking was challenging and exhausting, and the nerve pain was intense and disorienting.

On top of the physical challenges, it was an extremely emotional and anxious time as I struggled to accept my distorted face, not knowing how long the recovery would ultimately take, or whether I would be able to fully recover. My prognosis was good, and doctors were reassuring, but this condition has a tendency to surface many fears and insecurities, and I found the experience emotionally isolating.

Cultivating a Culture of Care

The anxiety of this new diagnosis was compounded by uncertainty with how it would affect my work at a new job, where I wanted to prove myself as a dependable, hardworking member of the team. On top of that, I was nervous about returning and revealing my face, or seeing colleagues in virtual meetings where it would be impossible to hide my condition. My first, flawed inclination was to think that I needed to disclose it to my colleagues in advance of returning to work, not only to save myself from the emotional burden of sharing the news in person, but to also let them know that I was okay despite looking different. What I wanted more than anything was to work from home for a while. Not only to determine how my new condition would affect me, and be able to take breaks when the nerve pain got to be too much or my vision would not allow me to focus on the screen anymore, but I also wanted time to come to terms with a potentially long recovery, and space so that I would not have to navigate that challenging and personal experience in front of students and colleagues.

Isgro and Casteñeda (2015) describe a “culture of care” as one “where professional and personal lives can be integrated in meaningful and gratifying ways” (p.174). In their examination of motherhood in academia, they advocate for a culture of care as a conceptual framework that provides both the vision and tools toward organizational practices that respond to peoples’ needs, and in particular acknowledges the lived experiences of caretakers. Beyond the needs of caregiving individuals, however, they describe care as a universal need that benefits everyone, arguing that institutions can exhibit compassion for employees with a "multiplicity of lived experiences" (Isgro & Casteñeda, 2015, p. 179).

Offering flexibility in the workplace is one step toward establishing a culture of care that prioritizes employee health and wellbeing. In libraries, the COVID-19 pandemic accelerated discussions around the importance of flexible work arrangements (Albro & McElfresh, 2021; Hosoi et al., 2021). Prior to the pandemic, however, flexibility in scheduling and work location has been regarded as an important factor contributing to positive work experiences for librarians with disabilities (Oud, 2018), librarians who become mothers or have small children (Gallin-Parisi, 2017), and for librarians seeking greater work-life balance (Townsend & Bugg, 2018). My own experience with an idiopathic condition highlighted the stark reality that any person may become disabled in one way or another, either temporarily or not, at any time. It is clear that everyone needs some degree of flexibility, both for their physical as well as mental health and wellbeing.

The need for compassion and empathy in leadership is particularly critical in situations where the need for flexibility arises among staff (Hosoi et al., 2021). In practice, compassionate leaders can cultivate a sense of belonging among employees by exhibiting appreciation and recognition for their work, supporting their professional growth, and actively supporting the resources and practices employees need to succeed, including the provision of flexible work arrangements. In advocating for compassionate leadership, Falcone and McCartin (2022) note that "it is time to move from tolerance of remote work to acceptance and support of it" (p. 559). As we move out of the height of the pandemic, librarians and library workers need to reconsider the traditional power structures within organizations that no longer hold value in the modern workplace, and instead champion policies and practices that cultivate a culture that respects its employees by providing them what they need. Concerns about remote workers' productivity—despite the fact that autonomy is a major driver of job engagement (Bakker, 2011)—simply reinforce outdated and unethical notions that work holds higher value than the people doing the work.

This culture of care is not just created by leaders; it is also essential to have strong social support from colleagues. McLay Paterson and Eva (2022) highlight compassion and "relationships of care" as uniting factors between colleagues during the height of the COVID-19 pandemic. In examining collegial relationships, they found that care was centered when intentional effort was made to find time and space to connect with colleagues, and when empathy and consideration were provided for others' situations (McLay Paterson & Eva, 2022). Social support can satisfy a basic need for belonging, particularly in a shared experience of crisis such as the pandemic. We need, however, to be able to grant ourselves and each other compassion and empathy when we experience life changes on an individual scale, such as disability, childbirth, illness, injury, and mental health challenges. Stepping in for each other in times of need is a simple way to center care, promote belonging, and prioritize relationships among colleagues. Knowing that someone is available and willing to take additional shifts at the research desk or fill in for a class when you suddenly fall ill can provide a valuable sense of comfort and reassurance, allowing you time and space to prioritize your health. For librarians, reshaping perspectives on flexible work arrangements is vital to our success in the profession, and to our health as people.

I was lucky. My supervisor was completely supportive, giving me flexibility to work from home for as long as necessary. I had already witnessed the accommodating nature of the work culture in the Libraries, and when this flexibility was extended to me, I was immensely grateful. Particularly in the first few weeks, as I was learning new things every day about how this condition was impacting me, even with the scary uncertainty of the outcome, it was comforting to have autonomy over my health and know that I would not be forced to return to work before I was ready, or be forced to take extended leave if I was not. One of the Libraries administrators met with me shortly after the new year, and she was so kind and reassuring as she talked through the options available to me, including encouraging me to hold off any disclosure of my medical information. Because of my blurred vision, I was able to get an official accommodation through the Equal Opportunity Services office and work from home until I felt ready to return to work safely, just as an added layer of security.

Over these past few months, I have been thinking about how fortunate I am in my current role. I could not help but consider how this experience would have played out if I were still in my previous position, working in an understaffed department at a smaller academic library. In that job, my experience would have been very different; working in a public-facing department, I would have become a burden on my colleagues who would have had to work extra hours at the research desk to cover my shifts. I would not have been afforded the privacy of coping on my own time. I would have had to teach classes and provide research help, all while facing the insecurities arising from my changed appearance. Though my colleagues would have been willing to help me, understaffing would have limited their capacity for assistance and, ultimately, understanding. Working remotely for an extended period of time would not have been an option; I would have had to return to work in-person or drain my sick time and go on extended leave.

The privilege in my new position, both in my current job as well as the type of work that affords me the option to work remotely, is foremost in my mind when considering the gratitude I have for my role and the flexibility it provided while undergoing this experience. Though remote work was available, the most important underlying component was the culture that supported it, which made it both an accessible and acceptable option for me. This prompted me to interrogate my own paradigms about work and productivity, which felt out of place in this new context.

Interrogating Productivity and Commitment

There are many things we can do within our own libraries to establish a culture of care, including those in leadership and support roles. Most importantly, we can normalize a culture that prioritizes people over work. In her discussion of supporting librarianship and motherhood, Gallin-Parisi (2017) discusses the phenomena of "flexibility stigma" and "bias avoidance," whereby librarians eschew institutional policies for flexible work arrangements out of fear of being perceived as less "devoted" or committed to work (p. 7). This is particularly true for librarians with disabilities, as the stereotypes about their productivity often leads librarians to avoid requesting official accommodations unless absolutely necessary (Oud, 2019).

When there are less clearly-defined processes around flexibility at work, this can be even more challenging for librarians to navigate, though policies alone are not always effective in changing culture. In studying employee engagement and turnover intentions in organizations with flexible work arrangements, using a large sample of employees from banking, educational, public service, and community service sectors in Australia, Timms et al. (2014) found that employees may not consider formalized flexible work policies viable due to the informal processes and unwritten cultures within organizations that do not support employees' use of them.

Libraries are not immune to this acculturation. If anything, the service-oriented nature of the work makes us more vulnerable to this. To challenge this default model of work, organizations—and the people within those organizations—must normalize the use of flexible work arrangements. Though clearly defined and formalized written policies are important, it is essential that people within the organization actually use them, and for a variety of reasons. Otherwise, over time it can easily become a false option that subverts the organizational culture and manipulates eager professionals to sacrifice healthy boundaries in an effort to demonstrate "commitment"—even if (or more often, when) the organization is not committed to them.

Another thing that library leaders and workers can do, beyond normalizing use of flexible work time, is to honor that flexibility, and grant employees the autonomy and respect to use that time in a way that works best for them. Employees should not be made to feel like they need to be glued to the computer and available at a moment's notice if they are working from home; not only is this not realistic (even when working in the office), it promotes a toxic culture of surveillance that assumes that employees have bad intentions. This type of expectation can promote overworking, even when flexible work arrangements are codified and used regularly. In fact, Timms et al. (2014) found that flexible scheduling can contribute to blurred boundaries in work hours and, subsequently, perceived commitment and engagement. This reinforces the phenomena of flexibility stigma and bias avoidance, which have potential to detrimentally impact new professionals in particular, as they are less likely to be familiar with the expectations of the work culture. This has even more implications for librarians seeking promotion, who may feel pressure to continue excelling in order to meet potentially subjective promotion criteria.

The need for flexible work arrangements, and the stigma around requesting them, especially impacts librarians with disabilities or illnesses. As Brown and Leigh (2018) describe in their article addressing this more broadly in academia, academics with disabilities or illnesses often find themselves compromising other parts of their life for their work more so than their able-bodied colleagues. Concerns about productivity and workload were echoed in Oud's (2019) study on academic librarians, who noted that "doing more with less" introduced unique difficulties for people with disabilities due to their need to rely on different strategies, or their need for more time, to complete their work (p. 179). In addition, librarians with disabilities also confront stereotypes about their productivity, increasing the pressure on them to do more. In order to challenge these stereotypes and the unhealthy valorization of productivity that underpins them, leaders can and should create a positive work environment by building interpersonal relationships with their staff based on understanding of disability, and by providing appropriate support (Oud, 2019).

Though my current organization does a good job of challenging these problematic norms around work, productivity, and perceived commitment, this is a wider issue across other libraries that can, and need to, do better. The profession must confront the increasing demand on our diminishing staffs (2021-22 ACRL Research Planning and Review Committee, 2022; Kim, 2023). This essay is an attempt to add to the conversation, and a message to institutions that can and should do better. It is also a message to myself (and other librarians like me), to remind myself to critique the insecurities that motivate me to work longer hours, especially when using flexible work options. I find myself reverting to previous concerns of surveillance and "not showing my commitment" by working through the time I would normally use to commute. While working remotely for an extended period of time during the peak of my condition, I found myself confronting these default paradigms about work expectations, and I had to remind myself that I no longer work at a place where performance expectations are in a nebulous upward trajectory. I no longer need to guess where to pinpoint "enough" in the spectrum of work.

Conclusion

It has been about nine months since my diagnosis. I have regained most of the movement in my face, though my progress has not been linear. Improvements over time have been accompanied by new involuntary muscle movements and residual nerve pain. My eye muscles have again become a source of unpredictability and frustration, twitching persistently throughout the day, but this no longer affects my vision the way it did during the first few months. I am experiencing more muscle tightness in my face, and certain facial expressions cause new, odd muscle movements. Each week, each month that goes by, offers some new sensation or movement, mostly invisible to others but distracting and disorienting me throughout the day.

Despite these ongoing challenges and knowing that I still have some distance to cover on the road to recovery, I am grateful for my progress thus far, and for the unexpected opportunities that arose from this experience. Working from home for three months allowed me to spend more time with my 19-year-old cat, who was suddenly diagnosed with a brain tumor and, ironically, losing sensation in one side of her face just like me. Losing her was the hardest part of the entire experience, but I cherish the time I was able to spend with her.

In the first few weeks, it was so difficult to not be able to smile, but despite this—even when it was hard to be optimistic—I was able to find sources of happiness and joy. My friends and family were tremendously supportive, validating, and empathetic, and that helped me through the experience more than anything else. My workplace, both the culture and the people, also became an important source of support and compassion that helped give me space to process what was happening and time to figure out what I needed. It gave me an opportunity for self-reflection, and ultimately helped me come to terms with some of my own self-imposed expectations of productivity that had become enmeshed in my mind with self-worth and value. Difficult as this experience was, it forced me to face my flawed perspective and challenge it in a new, and necessary way. And even though my face is not quite the same, the change has ultimately been for the better.

Libraries can reshape traditional norms and expectations around work, leading with compassion and respect by prioritizing the lived experiences of employees. Care is a common good that benefits everyone, and building this into the organizational culture can empower employees to bring their work and life into balance. As Townsend and Bugg (2018) describe, providing clear and transparent policies, flexible work hours or locations, support for childcare and other caregiving roles, and options for stopping a tenure or promotion clock are all benefits that can empower librarians to prioritize their health and autonomy. More importantly, when employees are encouraged to avail themselves of these benefits, libraries can create a culture that ascribes value to the person beyond their productivity. In this culture of care, all individuals can thrive in both their professional and personal lives.

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