[Vote for discussion topics here]

Disability advocacy, care, and library work

Haŋ, toked yauŋṗi he? Jessica Schomberg emakiyapi ye. Thank you for taking time to be here today.

I am a disabled librarian working on the ancestral homeland of the Dakota people, and am currently in the process of learning the Dakota language. Learning a new language as an adult is an often-humbling experience, as every moment I speak or listen is a struggle, and I perform with less skill than a child. But this practice in being humble is a good one for me and for anyone engaging in disability advocacy work, as there is more to know about human difference and accessibility practices than any one person can do on their own. This is always a group activity and, as in my Dakota class, the best way to learn is to ask for help and share your knowledge with others. We all have something to bring to this conversation.

In this spirit, most of this session is planned around the question & answer portion. If you have any questions along the way, or questions about things that I don't touch on during my planned remarks, please ask them when we get to the q&a and hopefully we can collectively answer them then. I will probably go off script at some points, but I did provide a link to the written version of my prepared remarks in the chat, in case it's helpful for anyone.

Terminology

I was asked to talk about building an inclusive, caring workspace for disabled library workers, or library workers with disabilities. Some people prefer to self-describe using people-first terms (person with diabetes) and others prefer identity-first (T1 diabetic). I tend to use a mix of both and recommend asking disabled people their preferences if you need to refer to them specifically.

Using the name, pronouns, and group identification labels that someone uses for themself is an easy first step in creating a workplace that is caring and inclusive on a personal level. That is something each of us can do, no matter where we are in the workplace hierarchy. It shows a basic level of caring and courtesy, and also shows that you respect someone enough to honor their self-description.

That said, none of us have the right to demand that others share personal information that they're not comfortable sharing. I am open about having diabetes, so if a coworker asked me if I prefer person first or identity first language to self-describe, we could have a good conversation. If a coworker asked me to disclose medical conditions I hadn't already shared with them, we would not have a good conversation.

Breaking Down Barriers

In the social model of disability, disability is viewed as a political concept. Rather than focusing on the specific impairment or medical diagnosis a person may have – like in my case, my busted pancreas – the social model focuses on the structural and institutional barriers that discriminate against people like me, that prevents us from fully participating in any area of public life.

In libraries, again using my diabetes as an example, barriers could look like food and water prohibitions or being unable to take breaks to treat low blood sugars as needed. This could also look like a lack of available documentation or documentation written in a really confusing way (*cough* RDA) – because if I've been struggling with blood sugars, it can be harder for me to focus my eyes or read, and the reminders contained in good documentation can help me perform more effectively.

One clear way of reducing barriers then, would be to ensure that we're providing good documentation for all employees. As with many things that help a disabled person, like me in this case, it would also help new employees who are being trained. Good documentation also helps supervisors ensure that employees know what they're expected to do, and helps employees be confident that they're doing the right thing. As we're looking at reducing barriers, even if the move is prompted by the request of one person, it's good practice to remember that this one change can have positive spillover effects for others as well.

Working to reduce barriers means noticing gaps between what people want to do and what they're able to do, and instead of telling the person that **they** need to change, consider modifying physical structures and policies. I am now going to ask you all a long list of questions. I don't need answers to these questions; I'm posing them with the goal of directing your attention to some areas where barriers commonly exist in workplaces.

[Discussion option 1: Do you want to talk about workplace accommodations?]

Look at hiring practices. Do job postings include things that aren't strictly necessary for the position, like being able to lift a certain amount for a position that is mostly sedentary? Are accessibility options provided up front? Look at how people are expected to schedule their work time – do they have enough uninterrupted time to focus? Do they have opportunities for flexibility?

Do employees have to have a personal smart phone or home internet to fill out the daily covid survey before coming to work? Is public transit safe, accessible, and regularly scheduled?

What adaptive equipment could be provided – speech recognition software, modified keyboards, captions or transcripts or microphones during speaking events, chairs behind the library circulation desk?

How does communication happen in your organization – do meeting agendas come out in advance so people can prepare themselves for whatever topic is going to be discussed? Do meeting minutes come out quickly enough for people to feel like they're still "in the loop" even if one of their workplace accommodations is to not attend meetings?

Think about these things with the idea that you won't know all of the disability barriers your coworkers are experiencing. You won't know that your neighbor to the left has debilitating anxiety attacks. You won't know that your neighbor to the right experiences chronic pain. And even if you do know their specific diagnosis, that won't tell you everything about their daily experiences.

[Discussion option 2: Can you think of one workplace barrier that you can work to remove?]

Building Care

We've already talked a little about building a workplace of care. This care-building happens from listening to and respecting how people define themselves, it happens by making it safe for people to share those parts of themselves that they want to share. It happens through proactively looking for potential barriers to participation, and working to remove them before they exclude people.

[Discussion option 3: Do you want to talk about some cautions related to building a culture of care?]

At my workplace, I've been working with my fellow union members to build a disability advocacy caucus. This equity caucus is led by people with disabilities. In addition to advocating for the needs of people like ourselves, like demanding that HR publicly post agreed-upon steps of the ADA accommodations process, having this caucus also provides opportunities for access intimacy. If you're unfamiliar with that term, it was coined by disability justice activist Mia Mingus to describe the sense of connection and belonging you feel when you talk with people who have similar access needs to yours.

In a nutshell, the sense of access intimacy I often feel in spaces with fellow disabled people means I can say that I'm too tired to do something because diabetes, and the response is supportive and understanding. Access intimacy also allows me to talk with another disabled person about our conflicting accessibility needs, and work together to find a solution that works for both of us – that might be finding foods that neither of us are allergic to for a shared meal. It might also be, to use someone else's example, setting up a schedule of meeting attendance in which a person with a service dog and a person with dog allergies can alternate between being physically present and teleconferencing. Access intimacy allows people to openly discuss their access needs with confidence, because they know they won't be shamed or blamed or ignored.

[Discussion option 4: What one aspect of this topic do you want to know more about?]

Closing

People with disabilities have unique insights that we bring to discussions about workplace culture and well-being. We need to make sure that every disabled library worker is supported in a way that helps us thrive and helps the institution achieve its equity goals.

My work in this area has been heavily influenced by Black feminist thought, both broadly and within librarianship, including but not limited to the work of librarians Fobazi Ettarh, April Hathcock, Dr. Amelia Gibson, Stephanie Sendaula, Anastasia (Stacy) Collins, Dr. Nicole Cooke, and many others. I have also been compiling a bibliography of articles that specifically focus on disability in libraries. If you're interested in learning more after this session, these are great place to start.

Questions I expect to come up during the Q&A

How do I know what kinds of accommodations to ask for?

I highly recommend making use of the Job Accommodation Network: https://askjan.org/

Why didn't you talk about intersectionality and disability?

Because it's such a huge topic! Oppression based on race, class, gender, sexual orientation, religion, etc., intersect with disability so deeply and in so many ways that I struggled – and failed – to come up with a brief explanation that would make any sense to a beginning learner. If you're interested in this, I highly encourage you to read pieces by Imani Barbarin, Lydia X. Z. Brown (@autistichoya), Mia Mingus, and other disabled people of color. Also, the book and podcast *Disability Visibility*, hosted by Alice Wong, often takes an intersectional approach to topics of representation.

What is disability? How do I know if I have a disability?

(The following is influenced by *6 General Types of Disabilities* by Trish Robichaud.)

The definition of disability is contextual, and who gets labeled with which disability is also contextual (intersectionality plays a big role here).

Within the U.S., a person with a disability is basically anyone qualifying under the definitions in the Americans with Disabilities Act (1990, and 2008 Amendments and various judicial decisions). Yes, this is messy. Some conditions defined as disabilities are readily apparent to others, some are not. Some people have one condition, some people have multiple overlapping conditions. All people with these conditions have the right to ask for accommodations to support their ability to succeed.

People with disabilities may have conditions including but not limited to the following. For some of these conditions, assistive devices and universal accommodations can make them essentially non-disabling. For other conditions, assistive devices and accommodations can make them less disabling. Disability categories are conceptualized differently by different people, the way these conditions are grouped is not a universal standard.

1. Physical disabilities, including physiological, functional, and/or mobility impairments that are visible or invisible, permanent or intermittent. Conditions include cerebral palsy, dwarfism, Parkinson's, paraplegia, and many more.

2. Visual disabilities, including a spectrum from totally blind to low vision. Conditions include having cataracts, diabetic retinopathy, glaucoma, and many more.

3. Hearing disabilities are also on a spectrum, including people who have profound hearing loss, people who acquired hearing loss in adulthood, and people who use hearing aids or other assistive devices to augment their hearing. Conditions include being D/deaf, deafened, DeafBlind, and hard of hearing.

4. Mental health disabilities include mood disorders such as depression or Seasonal Affective Disorder, anxiety disorders such as phobias and PTSD, eating disorders, personality disorders, schizophrenia, and more.

5. Neurodevelopmental disorders are a broad range of conditions which can be caused by environmental conditions such as poverty, genetic conditions, and trauma. They often affect the learning process, and "may interfere with the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical skills" (Homewood Student Affairs). People with these disabilities can succeed in educational and work settings with the right supports. Neurodevelopmental disabilities include ADD/ADHD, autism spectrum disorders, dyslexia, tic disorders, traumatic brain injury, and more.

6. Medical disabilities or chronic illnesses include cancer, diabetes, fibromyalgia, HIV/AIDS, multiple chemical sensitivity, pain conditions, and many more. These conditions often fluctuate over time and can take a long time to diagnose properly.