

What It Means for a Disabled Librarian to "Pass": An Exploration of Inclusion, Identity, and Information Work

Shanna Hollich, Wilson College, USA

Abstract

Through autoethnographic research and a deep dive into theoretical literature, this article explores the idea of hidden or invisible disability and its impact on information work. Much of the current work on disability in higher education is focused on issues involving serving students or library patrons with disabilities. A less explored area of research focuses on the experience of being a library worker with a disability and how that may affect the nature of information work and the provision of service. Moreover, the author explores the repercussions of performing information work with a hidden disability, and how the nature of hidden disability and the act of passing brings about its own ethical quandaries and challenges. The conclusion discusses practical applications for working with colleagues who may have hidden disabilities and provides questions for further exploration.

Keywords: autoethnography; disability; identity; inclusion; librarianship

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Introduction

hat is the nature of identity? This is a question better suited for a philosophical treatise, perhaps, than a scholarly work at the intersection of disability studies and information science, but here we are nevertheless. The idea of disability itself is a nebulous one: what "counts" as a disability? How disabled do I need to be to call myself disabled? What about temporary disability? What about chronic illness? Where do we draw the line between abled and disabled? Where do we draw the line, if any, between disability and illness or disease? What does it mean to be disabled if nobody knows that I'm disabled? If no one can see it? If it's private, if it's hidden, if I pass?

As a librarian, an information worker, it is a regular part of my work to answer questions. Sometimes those questions are things like, "Where is the bathroom?" and "How do I make this stapler work?" Sometimes the questions are less tangible, more like the ones asked above. Sometimes the questions are even deeper, going right to the core of what it means to be a professional providing service to the public: What does it mean to be marginalized? How does my identity interact with and influence the work that I do? How can I be sure that my work is truly inclusive of all people?

In an attempt to explore some of these thornier questions, we must first unpack and discuss: what it means to be disabled, what it means to be a disabled library worker, the idea of



passing and hidden or invisible disability, and how these concepts interact with each other and impact the idea of identity and its relationship to information work. This paper focuses primarily on one central question: what does it mean to be a disabled library/information worker?

A Note about Language

There is much debate both within and outside of the disability community about proper terminology; this debate can generally be summed up as a preference for "person-first" versus "identity-first" language (e.g., Callahan, 2018; Thorpe, 2017). I primarily use person-first language here because of personal preference. However, when quoting other sources, I have chosen to retain the language of the original source without additional editing or comment. Above all, I respect the right of disabled adults to choose the language and terminology that they prefer when identifying themselves.

Moreover, the word "disability" is subject to multiple legal and colloquial definitions, all of which attempt necessarily to limit the scope of disability. I will not limit this discussion to any one definition of disability. Indeed, the central thesis here is that the idea of disability is much broader than these definitions would allow and includes physical disabilities, mental disabilities, chronic illnesses and conditions, learning and developmental disabilities, and also temporary or other impairments. This broad approach includes people who may not label themselves "disabled" but who may still belong to one of these categories or meet the criteria outlined in certain legal definitions; in fact, it is this question of identity and labels that I explore here.

Literature Review

Models of Disability

There are multiple ways to approach the idea of disability, and the scholarly literature throughout the last few decades has used various theory-driven models to ground work in disability studies. It is worth briefly examining the history and development of these different models of disability in order to provide an appropriate context for this work.

For the layperson (including most legislators), the medical and perhaps rehabilitation models of disability are the most prevalent. The medical model dominated much of the early- to mid-20th century and focuses on individual impairments, often without acknowledging the person behind the impairment. This model is still dominant in much of the medical field's training and discourse (Dunn & Andrews, 2015). In this model, disability is treated as a problem to be fixed with medical correction. Similarly, the rehabilitation model views disability as a problem that, even if medical intervention fails, can be solved by an individual learning to use assistive devices or other strategies to mimic as closely as possible the behaviors and activities of an abled person. Both models have their roots in a moral model of disability that views disabled people as inferior, objects of pity or scorn, and/or symbols of sin and vice that are in need of charity and grace. Under these models, disability is a personal problem, applicable only to the disabled individual, and the onus is on the disabled person to conform to abled societal standards.

Disability activists, beginning in the mid- to late-20th century, began to develop new ways of



thinking about disability as a direct reaction to these models. Social models of disability are based on the premise that disability itself is a neutral condition. This is the model that led to person-first language, which was a direct attempt to counter the dehumanization that was common with earlier medical models of disability (Dunn & Andrews, 2015). Rather than as a moral failing or a problem that needs to be fixed, the social model sees disability as a social construct imposed upon an individual by society at large. In this model, for example, the problem lies not with the individual who uses a wheelchair for mobility but rather with the society that lacks ramps and automatic doors. The onus is on society to provide accommodations and conditions that are accessible for all people rather than to force disabled individuals to conform.

Critical disability studies, including disability critical race studies (or DisCrit), take the social model of disability one step further. Inherent in the social and critical models of disability is the idea that disability is an integral part of an individual's identity (Annamma, Connor, & Ferri, 2013). Therefore, it may not be possible or even desirable for disabled individuals to conform to societal standards of "normalcy." Like minority models in related fields, critical disability studies contend that the lived experiences of a disabled individual are important in their own right and that they provide useful and necessary insight into the power dynamics of our culture (Reaume, 2014). Models like DisCrit ask us to see disability as one of a number of marginalized identities and to recognize that disabled individuals are a group disenfranchised from mainstream society in ways similar to those who are disenfranchised because of race, class, gender, or sexuality.

The autoethnographic work of this paper is primarily grounded in the social and critical models of disability. As a disabled person, I hold an identity that is marginalized by mainstream society, and this necessarily informs both the ways that I perceive and interact with the world and the ways in which various cross-sections of society interact with me.

Library Workers with Disabilities

There is a growing extant body of work that explores the idea of disability in public and higher education, particularly when it comes to serving library patrons with disabilities (e.g. Gibson & Hanson-Baldauf, 2019; Pionke, 2016a, 2016b; Pontoriero & Zippo-Mazur, 2019). Much of that current work is outward-focused rather than inward-focused; that is, it primarily explores the issues and challenges regarding serving patrons with disabilities but does not often explore the perspective of what it is like to be a library worker with a disability and how that may affect the nature of information work and the provision of service.

There is some existing work about library workers with disabilities, much of it centered on the experiences of academic librarians (Oud, 2018; Oud, 2019; Schomberg, 2018; Schomberg & Cole, 2017). The winter 2019 issue of *Library Trends* devotes an entire section to the experience of library workers with disabilities (e.g., Brown & Sheidlower, 2019; Pionke, 2019; Schlesselman-Tarango, 2019), and a recent article in *American Libraries* highlighted the barriers that disabled library workers face when job-hunting (Ford, 2018). Much of this work reports similar findings. Library workers with disabilities face discrimination and harassment due to their disability and are less likely to hold management or supervisory positions. They may be assumed to be less capable, less skilled, or less productive. Awareness of disability-related issues by librarians in management or supervisory positions is reportedly low, which means that those who are in positions of power most capable of making workplaces more



inclusive and accessible are unlikely to do so since they are unaware of the problem (Oud, 2018). Schomberg and Cole (2017) note that

For a person with disabilities, the social and cultural power dynamics; the inaccessible physical spaces in which they must operate; and the struggle with their specific impairments or body image can have lasting impacts on how they perceive themselves, on how others perceive them, and on how they understand the ways in which others perceive them. (para. 42)

Furthermore, workplace and societal circumstances mean that some people with disabilities will never disclose their conditions due to fear of disrespect or lack of confidentiality, eliminating their ability to receive necessary workplace accommodations. Some library workers, due to a fear of hostility or suspicion if they are "outed" as disabled, will spend much time and effort to "pass" as abled, often by concealing their identities or minimizing the effects of their disabilities to be seen as "normal" (Schomberg, 2018).

Many people assume that with legislation such as the Americans with Disabilities Act (ADA) of 1990 (amended in 2008), disability problems in the workplace have been solved. Of course, reality is not so simple. Schomberg (2018) outlines some of these issues:

Legalistic approaches to disabilities such as the Americans with Disabilities Act requires that people with disabilities disclose their conditions in order to access legal protections. However, those disclosures are not always treated with respect or confidentiality. What seems like a reasonable accommodation to the person with a disability will not always be viewed similarly by a human resources or university finance officer. There are also expectations that disabled employees will justify their hiring by "overcoming" their disability or being otherwise inspirational. (p. 117)

Oud (2019) discusses evidence that there is unconscious bias towards librarians who are non-white or disabled. Other workplace barriers include: "the invisibility of disability at work, a lack of understanding of disability, and stereotypical views of people with disabilities as less capable workers, leading to both overt and subtle forms of discrimination" (p. 7). These subtle forms of discrimination could include less access to training and professional development opportunities, less involvement in decision-making or leadership opportunities, and less access to promotions or merit-based salary increases.

Perhaps more importantly, legal solutions like the ADA require disabled individuals to disclose their disability status and formally request accommodations. This puts the burden on the individual to identify that they need help, feel comfortable disclosing to others that they need help, in some cases figure out what type of help or accommodation they might need, and then implement those accommodations and explain them to curious coworkers and clients. Furthermore, there is no guarantee that a request for accommodation will be granted. The ADA does not specify exactly what is meant by "reasonable," and often an employer will decide that an employee's request is unreasonable and communicate this fact by turning down the request, not taking it seriously, or sometimes by accusing the disabled individual of faking it or otherwise abusing the system. Additionally, a request for accommodation necessarily makes an individual's disability status public to some degree. At a minimum, a supervisor or a human resources representative will need to know; depending on what accommodations are needed, an entire office may discover sensitive and private medical information about an employee. It



is no surprise, then, that many disabled people choose to remain silent, if and when they can, for fear of harassment, discrimination, stigma, or reprisal.

The Idea of Passing

Many disabilities are invisible to the casual observer, such as some learning disabilities, cognitive disabilities, and mental health disorders. There are also physical disabilities that may have no obvious outward effects, including conditions like diabetes, hypertension, chronic pain, endometriosis, and infertility. As life expectancies have increased and modern medicine has improved, conditions such as these, which used to cripple or even kill people, are now being managed with no obvious physical effects and are frequently classified as disabilities. This is a natural consequence of the rise of social and critical models of disability. Modern definitions of disability have broadened to include illnesses and chronic conditions, like diabetes, that were not previously considered disabilities writ large. And though many of us are used to the idea that you cannot see whether or not someone has a mental illness or a memory deficit, many of these chronic illnesses are similarly unable to be seen. Thus, many people with hidden or invisible disabilities such as these are able to pass as abled, at least at some times and in some contexts.

Disability at its core has a dynamic nature—some disabilities are temporary or short-term, others are long-term, and a single person could pass in and out of disability multiple times over the course of their life. Those with hidden disabilities often receive two-fold stigmatization: there is the stigma that comes with being a disabled individual, such as rejection, ableism, and discrimination, as well as the additional stigma of not appearing disabled enough to need accommodations or support services. Some people with hidden disabilities report having extra difficulty receiving support services as compared to their visibly disabled colleagues because they need to jump through the extra hurdle of proving that they really need help (Kattari, Olzman, & Hanna, 2018). Think of this classic story: a disabled person with limited mobility sometimes needs an assistive device, such as a cane, to walk. They have a permit that allows them to park in designated disabled parking spaces, and they frequently do so. They drive to the store and decide this trip will only take a few minutes, they are feeling pretty good that day, so they leave the cane in the car to run their quick errand. A passerby complains, perhaps shouting something like, "Hey! Faker! This parking is for actual handicapped people!" not knowing that this person is following legal and ethical guidelines and is well within their right to that space. These confrontations, along with microaggressions that perpetuate ableism ("You speak really well for a deaf person!" or "How lucky for you that you get to bring your dog everywhere you go") can make life with disability even more difficult and frustrating than it might already be.

The idea of passing, then, is appealing in many contexts. If I can convince other people that I am not disabled, then I can receive all the attendant privileges of being abled without any stigma. Passing is often seen in the context of other marginalized identity groups, particularly those regarding race, gender, and sexuality. History abounds with stories of light-skinned African-Americans who passed as white in order to escape the brutal realities of slavery and racism, Shakespeare finds much inspiration in the idea of women dressing up and passing in society as men and vice versa, and many LGBTQ+ people are familiar with the idea of acting straight in certain situations where it may be unsafe to come out and be unapologetic about who they really are.



Passing only works, of course, in situations where one is close to the dividing line between two groups. Only light-skinned African Americans could pass as white, because skin color is the main way that humans divide each other into racial categories. It is widely understood that to be classified as white, a person's skin color can be certain shades of white, beige, tan, or even light brown but never dark brown or black. A person with prominent secondary sex characteristics that we commonly associate with femininity (a large bust size, wide hips with a narrow waist, certain facial features) might have a more difficult time passing as male than a person with a different body type. Similarly, our preconceived notions of what constitutes disability make it easier for some disabled people to pass more easily than others. Critical models and even many legal definitions of disability already recognize that disability status is a liminal space, one that is fluid and can change over different periods of time and in different contexts. A person with a hidden disability and skill enough to move through these different contexts without arousing suspicion might choose to pass as abled.

Hidden Disabilities and Information Work: My Story

I am a person with multiple hidden disabilities, and this fact informs the way that I view and interact with the world. I was not always disabled; or, perhaps I was, but I did not always think of myself as such. I have struggled since early childhood with mental illness, but it was not until my early 30s that I was formally diagnosed—at what point do I decide that that counts as a disability? My physical disabilities, likewise, did not manifest until my 20s and 30s, and each of them began as what I hoped might be a temporary illness but turned out to be chronic and incurable. My diabetic body, for example, is inherently different from my former non-diabetic body. Every decision I make about food, physical activity, clothing, whether or not to go outside for a walk—each of these choices is informed and constrained by the physical limitations of my diabetic body. In some respect, all of our choices as humans are informed and constrained by the physical limitations of our corporeal selves. But there is something about life with chronic illness, with disability, that makes this idea more present than it otherwise would be.

My decision to claim my disabled identity and to discuss it openly is a difficult and continuous one. Not only have I become aware of the privilege I held as a white non-disabled woman, but I am also keenly aware of the consequences of openly acknowledging my disability status and losing some aspect of that privilege. I worry about discussing my medical status and diagnoses. Will I receive judgment from friends, from family? Will I be treated kindly? Fairly? Like a fragile being who can no longer make decisions for myself? What about work? Will disclosing my disability status tank my career? Will my boss no longer trust me with leadership responsibilities or high-visibility assignments? Moreover, these questions must be asked and answered over and over again, in every new situation where my disability status must be potentially disclosed, in every new job, in every new interaction.

The iterative nature of this process cannot be stressed enough: These questions never go away. Passing, much like disability status and other markers of identity, can itself be a liminal state. Skyhorse (2017) equates it with "performance" (p. 7). But, perhaps most importantly, passing is not always all-or-nothing, and it is not always deliberate. Because my disabilities are hidden, I frequently pass even when I do not intend to. Depending on the context, even people who know that I am disabled will forget, including those who might treat me poorly based on my disability status. Passing is often thought of solely as intentional, as a conscious or premeditated decision we might undertake to gain an explicit comfort or advantage, and



sometimes it is. On the other hand, as the editors point out in We Wear the Mask (2017),

Whether you've been conscious of it or not, passing is a privilege that all of us have indulged in at some point. People make assumptions about us based on stereotypes, context, environment. When we don't correct these ideas, either because we genuinely like the assumptions someone's made about us, or because explaining the truth could humiliate, or infuriate, whoever's making these assumptions, we 'pass.' We misrepresent ourselves in classrooms or at airports, on Facebook and at dinner parties. Maybe we haven't reached Rachel Dolezal's level of racial performance, which incorporated hair weaves and skin tanners, but each of us sometimes employs misdirection to let someone jump to a different conclusion about who we are. (p. xii)

As a queer woman, I analogize this process to that of coming out. I often pass as a straight cisgender woman, particularly since I am married to a straight cisgender man, and so I must continually come out as queer when I meet new people and am in new situations if I want my true identity to be known. I imagine that those of us with hidden disabilities, when we need accommodations or otherwise want to be seen for who we truly are, must sometimes consciously come out in a similar fashion.

It is important to reiterate, however, that the decision to pass is not always purposeful. I do not consciously choose to pass as straight, cisgender, or abled, either at work or in my personal life. But I pass because of the default assumptions that society makes about people who look like me. No matter how out I am, no matter how much of an outspoken advocate I may be, there will always be contexts and situations where people, even people who know my disability status, will assume that I am not disabled or forget my limitations and where I will have to make a choice: reiterate and continually assert who I am and what that means, or pass. Failure to make a conscious choice results in a default assumption that, in most instances, means I end up passing.

What impact does all this have on my role as an information worker? Like any aspect of my identity, the impact is both major and omnipresent while often being ignored, unrealized, or relegated to the background. I have not yet needed formal accommodations at work, so I have no personal experience with recalcitrant supervisors or human resources personnel. Much of the wider campus community likely has no idea that I am disabled. I feel some ambivalence about this, and I am sure that that has some effect on my interactions at work, although I am not entirely aware of exactly what those effects might be and whether their impact is positive, negative, or neutral. I am a person who often brings my whole self to every situation and I am unused to any level of prevarication, so passing sometimes feels akin to lying or pretending. Again, the editors of *We Wear the Mask* (2017) explain the struggles that those of us who pass, deliberately or not, often face:

Each of the fifteen writers in this collection had to wrestle with serious questions in their own specific way: Have they passed as someone they were not? What was their agenda? What did they gain and lose from the experience? Were they worried about stoking feelings of resentment toward a specific community? Was it selfish pity by proxy? Were they mining the plight of other marginalized individuals or trying to rescue themselves from their own marginalized groups? How did each of these authors play on stereotypes (or sympathies) to pass? (p. xi)



As one can imagine, these are not easy questions to answer.

The crux of librarianship and information work is people. Librarianship, despite its stereotypical imagery of books and computers and typing at a desk, is first and foremost a service profession. My job is to facilitate the research needs of my campus community, and even when I am doing that by signing purchase orders or creating metadata, it is people who are at the heart of those endeavors. More commonly, my work involves sitting and talking face-to-face with faculty, students, and other staff members to identify and solve problems. Sometimes this work is sensitive. Sometimes the research students need help with is for personal, private matters outside of class. And, sometimes the conversations that need to be had in order to discover and work through an information need are real and raw and messy. It can be difficult to be fully present and engaged in those conversations if the act of passing makes me feel as if I am hiding an important, and sometimes relevant, piece of myself during these interactions.

I am also a supervisor of 25-30 undergraduate work-study students. Managing necessarily requires complex interpersonal skills, and I often find myself struggling with aspects of my identity as the employees who trust me will occasionally share struggles of their own. When an employee tells me that they have had to miss work so much lately because they have started a new antidepressant, do I tell them that I know that experience all too well? How much do I dare divulge when the line between empathy and oversharing is sometimes unclear? If my communications are more curt than usual, do I explain that it is because I am having a high-pain day? What aspects of my disabled identity are relevant, which will bring judgement and gossip, which will provide useful context?

There are also questions about the interplay between my identity and my information work that I am even less equipped at this point to understand or even unpack. These likely have to do with the very nature of humanity and bias, and we as a profession seem to be especially struggling with these issues now. Part of my job as an academic librarian is to teach information literacy skills, and those skills require a great deal of critical thinking. Every source must be vetted, every article must be carefully perused before it can be trusted. Due to my experiences with various medical issues over the years, I know that I am quick to judge certain types of research and writing more hastily than others. How do I keep these biases in check in the face of a world and a profession that is inherently not neutral? How do I react when I find ableist research—can I recommend it to my students, even if it is otherwise factually accurate? It has been suggested to me that these types of interactions could provide teachable moments, a way to engage in critical discussion about complex issues with students or even colleagues. However, as Ettarh (2018), Moeller (2019), and others have pointed out, this places an undue burden of emotional labor on me both as a disabled person and as an information worker. Though much of my personal work involves advocacy, this is typically unpaid labor that I take on outside of my working hours and is not an explicit part of my librarian job. As will be discussed in the final section, we cannot properly place the onus on individual information workers to educate, advocate, and provide solutions for what are actually systemic problems.

Finally, there is the issue of working with others who are also disabled. My hope is that I have built a culture of openness and trust in my work community such that students and colleagues with hidden disabilities are comfortable disclosing their disability status to me. If I know a student is struggling with mental illness, for example, I might be more mindful about checking in on their well-being during a typical reference interview. If I know that a student has certain



learning disabilities or cognitive disabilities, I can better tailor the resources that I recommend to them for their research, or even have a greater understanding of their mannerisms and their social behavior such that I don't take it personally if they, say, struggle to maintain eye contact or sit still while we converse. It is perhaps enough to approach all of our interpersonal interactions, at work or otherwise, with the understanding that we cannot fully know the context of another person's life, and that they are likely wrestling with their own personal demons. It is perhaps enough to give everyone the benefit of the doubt when they behave "oddly," to strive not to take every slight personally, and to make sure our interactions are free from microaggressions and other forms of discrimination. However, for most of us, this is quite a tall order. But at the same time, it is also a tall order to expect every disabled person to disclose their disability status in every situation, even when it might be relevant, even in situations where they might feel comfortable doing so. It is too much to ask those with marginalized identities to take on the work of continually advocating for themselves and educating others. Identity is complex and fluid, and these expectations assume a certain level of self-awareness and tirelessness that we cannot expect everyone to have. Again, as the social and critical models of disability make clear, these are not issues that can be solved at the individual level but rather will require systemic, societal change.

Conclusions and Practical Applications

As with many qualitative explorations, there are no easy answers here. In fact, I am certain that I have raised more questions during this exploration of disability identity than I have answered. Clarence Page (2017) suggests that

Each of us has two identities: the one that we know ourselves to be and the one that others see when they interact with us. 'Passing' is the label that we give to the practice of changing our public identity without, one hopes, losing track of who we truly are. (p. 153)

I am not certain this is possible—to change our public identity without changing who we truly are. I am not certain that who we truly are is something inherently separate from who we claim to be or from the way we choose to live. Though I have dealt with chronic illness for many years, I have only (comparatively) recently chosen to label myself "disabled," to claim that as a part of my identity, in the same way that I claim the labels "white" and "queer." This very act has changed the way that I move through the world, the way that I think about the world, and the way that I perform my work. As each of us grows as human beings and discovers more about who we are and who we would like to be, our roles in society and our interactions with others also necessarily grow and change. The social and critical models of disability, discussed previously, explicitly recognize the fluid and liminal nature of identity formation and interaction with the societal systems that cause these changes.

Still, there are a number of practical applications that libraries and information workers can take in order to better understand issues of hidden disability and marginalization. These are outlined below.

Trainings and Workshops

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There are trainings and workshops available to library staff about disability etiquette. The vast majority of these are focused on working with patrons with visible, not hidden, disabilities,



although this focus increasingly centers on inclusion in general rather than inclusion of any particular disability group. While disability-specific training is important, and already widely prevalent, the most useful trainings and workshops will involve aspects of cultural humility and awareness of implicit bias.

Cultural humility goes beyond a simple knowledge and understanding of cultures other than our own and challenges us to acknowledge, examine, and push beyond our own cultural biases in the process. There are a number of organizations that provide cultural humility training and discuss the difference between cultural humility and cultural competence, many of them focused healthcare sector, including Culturally Connected in the (https://www.culturallyconnected.ca/), ETR (https://www.etr.org/solutions/professionaldevelopment/), and NNLM (https://nnlm.gov/classes/serving-diverse-communities). Implicit bias tests and training, like those provided by Harvard University's Project Implicit (https://implicit.harvard.edu/implicit/takeatest.html) and Ohio State University's Kirwan Institute (http://kirwaninstitute.osu.edu/), can make information workers more aware of the biases that exist against those with marginalized identities and how systemic and prevalent that societal acculturation is.

Universal Design

What messages does a library send when all of its chairs have arms, when all of its counters are four feet high, and when all of its shelving units are spaced 18 inches apart? Universal design is a framework that forces us to think about people who are different from us and to alter our physical and digital spaces accordingly (e.g. Staines, 2012; Zhong, 2012). It attempts to make buildings, products, and environments accessible to all people regardless of disability status or other factors. This framework has been extended into instruction under the name universal design for learning (UDL), where the intention is to provide flexible learning environments that can accommodate individual differences.

Universal design provides a good first step in allowing fuller access to persons with hidden disabilities; after all, if physical design is modular, if instruction is flexible, and if multiple modalities are accommodated, it is not necessary for those with hidden disabilities to disclose in order to receive adequate service. However, universal design provides little guidance about what to do in scenarios where differing needs necessarily conflict or when flexibility is not possible due to structural limitations or lack of cultural awareness. No design can be truly universal, and the more we compromise in an attempt to meet everyone's needs, the more we may end up actually meeting no one's needs. More research needs to be done in this area to discover if universal design is truly meeting the needs of those with hidden disabilities or if it is solely or primarily focusing on those with the most visible disabilities and the most outspoken advocates. But, at a minimum, universal design and UDL provide a good example of how change can be enacted on a more systematic level, and these frameworks acknowledge that the onus is on society to make and adapt structures and designs rather than on the individual to take on the extra labor of adapting themselves.

Changes in Language and Terminology

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Works such as Drabinski (2013), Koford (2014), and Olson (2013) ask us to reconsider the language and relationships we use when we catalog and classify library materials so that we can better honor and acknowledge the identities of those in marginalized groups. This is an



important step toward creating a culture of library and information work that is more equitable, diverse, and inclusive. Are works about disabled adults in your library classified under outdated and possibly offensive terms? This could clearly cause discomfort not only to a student or patron searching for such materials but also for the information worker who has to work with them. Furthermore, this sends an implicit message to disabled workers that their language, their terminology, and by extension their experiences, are not valued, and this creates an environment where disabled employees choose to remain hidden, impacting their productivity and well-being in the process. Consider reviewing the terminology in your employee handbook, the subject headings in your catalog, and the shelving classification you use through a lens of cultural humility. Library of Congress Subject Headings can be changed; local authority headings can be established. Consider carefully the language and terminology you use when providing access to materials to your diverse community.

Banish the Myth of Neutrality

Despite the popular sentiment of the last few decades, we as a profession are beginning to come to grips with the fact that libraries are not inherently neutral (Are libraries neutral?, 2018; Bourg, 2015, 2018). It is important to realize that every choice we make or do not make is based on underlying assumptions, and interrogating those assumptions is a valuable use of our time. When you see a "young" person ask for a large print book, what assumptions do you make? What judgment happens in your mind when I choose to take the elevator instead of the stairs?

There has been much discussion in the last few years in the library community about what implicit messages we send to our patrons when we open up our meeting rooms to hate groups, for example; but, we should also be examining what messages these and other actions send to our staff and administrators as well. The decision to stay in a historic building that cannot be renovated in compliance with the ADA is not a neutral decision, for example. The decision to include physical requirements such as "must be able to lift 50 pounds" or "must be able to push a book cart" in our job postings is not a neutral one either. As we do the work to shift our culture and examine our biases, we need to examine the traditional trappings of librarianship and information work that we typically take for granted.

Build a Culture of Trust

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One of the reasons it is so difficult to provide answers here is that hidden disability is, by its very nature, hidden. In order to fully understand the experiences of those with hidden disabilities and work toward more concrete solutions (such as trainings, workshops, design, education, advocacy), it will be necessary to build a culture where those with hidden disabilities do not need to pass in order to survive. It is imperative that libraries and other workplaces make it clear that information workers with disabilities will be taken seriously and accommodated without adverse repercussions. It should also be made clear that accommodations for those with disabilities are a necessity, not a privilege or special advantage. Building a culture of trust among information workers and their colleagues as well as among the people they serve allows for an environment where those with marginalized identities can be fully and truly themselves, resulting in increased productivity, retention, and quality of work.

We could all certainly benefit from injecting a bit more empathy into our information work.



Identity is complex, and our responses to it will also necessarily be complex. There is no one-size-fits-all solution to accessibility and inclusion. The more time we spend interrogating our own biases and making space for others to explore their own identities, the more inclusive our librarianship will be.

References

- Annamma, S. A., Connor, D., & Ferri, B. (2013). Dis/ability critical race studies (DisCrit): theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education*, 16(1), 1-31. https://doi.org/10.1080/13613324.2012.730511
- Are libraries neutral? Highlights from the Midwinter President's program. (2018, June 1).

 **American Libraries Magazine*. Retrieved from https://americanlibrariesmagazine.org/2018/06/01/are-libraries-neutral/
- Bourg, C. (2015, January 28). Never neutral: Libraries, technology, and inclusion. Retrieved from https://chrisbourg.wordpress.com/2015/01/28/never-neutral-libraries-technology-and-inclusion/
- Bourg, C. (2018, February 11). Debating y/our humanity, or Are libraries neutral? Retrieved from https://chrisbourg.wordpress.com/2018/02/11/debating-y-our-humanity-or-are-libraries-neutral/
- Brown, R., & Sheidlower, S. (2019). Claiming our space: A quantitative and qualitative picture of disabled librarians. *Library Trends*, 67(3), 471-486. https://doi.org/10.1353/lib.2019.0007
- Callahan, M. (2018, July 12). "Autistic person" or "person with autism": Is there a right way to identify people? *News @ Northeastern*. Retrieved from https://news.northeastern.edu/2018/07/12/unpacking-the-debate-over-person-first-vs-identity-first-language-in-the-autism-community/
- Drabinski, E. (2013). Queering the catalog: Queer theory and the politics of correction. *The Library Quarterly*, 83(2), 94-111.
- Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264. https://doi.org/10.1037/a0038636
- Ettarh, F. (2018, January 10). Vocational awe and librarianship: The lies we tell ourselves. *In the Library with the Lead Pipe*. Retrieved from http://inthelibrarywiththeleadpipe.org/2018/vocational-awe
- Ford, A. (2018, November 1). Underrepresented, underemployed. *American Libraries*, 49(11/12), 38-40.
- Gibson, A. N., & Hanson-Baldauf, D. (2019). Beyond sensory story time: An intersectional analysis of information seeking among parents of autistic individuals. *Library Trends*,



- 67(3), 550-575. https://doi.org/10.1353/lib.2019.0002
- Kattari, S. K., Olzman, M., & Hanna, M. D. (2018). "You look fine!": Ableist experiences by people with invisible disabilities. *Affilia*, 33(4), 477-492. https://doi.org/10.1177/0886109918778073
- Koford, A. (2014). How disability studies scholars interact with subject headings. *Cataloging & Classification Quarterly*, 52(4), 388-411. https://doi.org/10.1080/01639374.2014.891288
- Moeller, C. M. (2019). Disability, identity, and professionalism: precarity in librarianship. Library Trends, 67(3), 455-470. https://doi.org/10.1353/lib.2019.0006
- Olson, H. A. (2013). *The power to name: Locating the limits of subject representation in libraries*. Dordrecht, The Netherlands: Springer.
- Oud, J. (2018). Academic librarians with disabilities: Job perceptions and factors influencing positive workplace experiences. *Partnership: The Canadian Journal of Library and Information Practice and Research*, 13(1). https://doi.org/10.21083/partnership.v13i1.4090
- Oud, J. (2019). Systemic workplace barriers for academic librarians with disabilities. *College & Research Libraries*, 80(2), 169-194. https://doi.org/10.5860/crl.80.2.169
- Page, C. (2017). Class acts: Ways to be something you're not. In B. Skyhorse & L. Page (eds.), We wear the mask: 15 true stories of passing in America (pp. 151-167). Boston, MA: Beacon Press.
- Pionke, J. J. (2016a). Sustainable library services for all. *Library Management*, 37(6/7), 317-325. https://doi.org/10.1108/LM-04-2016-0030
- Pionke, J. J. (2016b). Using new literacies to discuss disability in the library. In S. McNicol (Series Ed.), *Critical Literacy for Information Professionals* (pp. 57-63). London, UK: Facet.
- Pionke, J. J. (2019). The impact of disbelief: On being a library employee with a disability. Library Trends, 67(3), 423-435. https://doi.org/10.1353/lib.2019.0004
- Pontoriero, C., & Zippo-Mazur, G. (2019). Evaluating the user experience of patrons with disabilities at a community college library. *Library Trends*, 67(3), 497-515. https://doi.org/10.1353/lib.2019.0009
- Reaume, G. (2014). Understanding critical disability studies. *Canadian Medical Association Journal*, 186(16), 1248-1249. https://doi.org/10.1503/cmaj.141236
- Schlesselman-Tarango, G. (2019). Reproductive failure and information work: An autoethnography. *Library Trends*, 67(3), 436-454. https://doi.org/10.1353/lib.2019.0005
- Schomberg, J. (2018). Disability at work: Libraries, built to exclude. In K. P. Nicholson & M.



- Seale (Series Eds.), *The politics and theory of critical librarianship* (pp. 111-123). Retrieved from https://cornerstone.lib.mnsu.edu/lib_services_fac_pubs/149/
- Schomberg, J., & Cole, K. (2017, April 19). Hush...: The dangers of silence in academic libraries. *In the Library with the Lead Pipe*. Retrieved from http://www.inthelibrarywiththeleadpipe.org/2017/hush-the-dangers-of-silence-in-academic-libraries/
- Skyhorse, B. (2017). College Application Essay #2. In B. Skyhorse & L. Page (Eds.), We wear the mask: 15 true stories of passing in America (pp. 1-21). Boston, MA: Beacon Press.
- Skyhorse, B., & Page, L. (Eds.). (2017). We wear the mask: 15 true stories of passing in America. Boston, MA: Beacon Press.
- Staines, G. M. (2012). Universal design: A practical guide to creating and re-creating interiors of academic libraries for teaching, learning, and research. In Chandos Information Professional Series. Oxford, UK: Chandos Publishing.
- Thorpe, J. (2017, August 9). What is identity-first language, & should you use it? *Bustle*. Retrieved from https://www.bustle.com/p/what-is-identity-first-language-should-you-use-it-74901
- Zhong, Y. (2012). Universal design for learning (UDL) in library instruction. *College & Undergraduate Libraries*, 19(1), 33-45. https://doi.org/10.1080/10691316.2012.652549

Shanna Hollich (shanna.hollich@wilson.edu) is the collections management librarian at Wilson College. She received her MLIS from Rutgers University and completed her undergraduate work at Brandeis University. She previously worked as a K-12 librarian and her work in education and youth services has appeared in *Virginia Libraries* and *New Library World*. She most recently worked as a co-editor for the Winter 2019 issue of *Library Trends* about Disabled Adults in Libraries. Her research interests are general and varied and include issues surrounding accessibility, technical services, social justice, and labor, and she frequently presents on topics related to copyright, open licensing, open access, and scholarly communication.

