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Claiming Our Space: A Quantitative and Qualitative Picture of Disabled Librarians

ROBIN BROWN AND SCOTT SHEIDLOWER

ABSTRACT

Librarianship is made up of many different sorts of people. Until now, while research has been done on nondisabled librarians and who they are, little research has been undertaken on disabled librarians. This piece is based upon a research survey that draws on the experiences of librarians who are willing to self-identify as disabled librarians. The survey was further followed up by interviews. The authors want to enrich everyone's understanding of what it means to be a librarian and, at the same time, to be disabled.

INTRODUCTION

Do we really understand the glorious patchwork that is the librarian community? In the early twenty-first century, it is radically important that we reflect the communities that we serve. One of the facets of librarianship that is little understood and appreciated is the presence of disabled librarians in our community, and the contributions and challenges that they face. The coauthors of this article are both librarians with disabilities and began this project to find and support disabled librarians. In the early days of the research, it was enough to discover that we are not alone. The focus of the project became a call to claim our space within librarianship. We think that it is extraordinary that so many people with a wide range of differences have found a home in librarianship.

We want to truly draw out why the contribution of disabled librarians is a significant piece of librarianship. We want people with disabilities to know that librarianship is welcoming to people with a wide range of talents and challenges. We want the whole world to see what we see: the tapestry of people with all sorts of varied gifts, abilities, and deep challenges who are drawn into librarianship. This will be the result of this research survey,

drawing on the experiences of librarians who are willing to self-identify as disabled librarians. We want to enrich everyone's understanding of what it means to be a librarian and to be disabled. We want to claim our place within the larger community.

LITERATURE REVIEW

Defining Disabilities

Seeking a background to help us understand our survey led to an education in the field of disability studies. One of the most prominent conversations to jump out was about the difference between impairment and disability. What role does the environment play in the construction of disability? As an example, a mobility-impaired person can function alongside the able-bodied, as long as the elevators are working. The World Health Organization (n.d.) has defined the issues related to being disabled as follows: "Disability is . . . not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives."

Different scholars have interpreted disability in different ways. As Longmore (2003, 49) wrote, "Disability is primarily a socially constructed and stigmatized role." On the other hand, Shapiro (1993, 112) realized that "to be disabled meant to fight someone else's reality. Other people's attitudes, not one's own disability, [are] the biggest barrier." Brune and Wilson (2013, 2) analyzed disability and the lack thereof differently; when they observed that "rather than assume a dichotomy between disability and normality, an examination of passing from a disability perspective reveals how the social construction of disability remains fluid." All this is probably best summarized by Murphy (1990, 4), who concluded that while disability is a social construct, it nonetheless is imbued with its meaning culturally, thereby being "a social malady."

Although the social model is useful, particularly when seeking physical changes in the environment, there are writers who seek a more nuanced definition of disability. Tom Shakespeare makes the very strong point that the physical aspects of disability are a factor and should not be ignored (2014). Disability is created by an interaction between physical impairments and social barriers. Shakespeare emphasizes that the impact of physical health challenges on quality of life, the ability to work, and the choice to do part-time work should not be underestimated (31–33).

All in all, it is important to understand that the field of disability studies continues to wrestle with how to define such basic terms as *disability*. It is worth pointing out JJ Pionke's 2017 article, which makes the point that everyone is simply "functionally diverse." This gets around the language that often describes disability as a deficit, some form of "less than." It also

avoids the “person-first” language that makes some people with functional diversity uncomfortable.

What Drives Ableism?

Any discrimination toward someone with a disability is labelled as ableism or, sometimes, disablism. The able-bodied often do not understand that everyone will become disabled, that it is a natural part of aging (Garland-Thomson 1997). There is also fear of difference (Stiker 1999) and an unwillingness to confront the daily occurrence of becoming disabled due to illness or accident (Siebers 2008). Many people also have a fear of confronting an uncomfortable reality and what it means to cope with a disability. Stiker (1999) argues that the fear of difference is part of our humanity.

Disabilities and Library Workers

Johnstone (2005) suggests including people with disabilities in the staffing of academic libraries. This allows students to have experiences with disabled workers, consequently changing society-wide attitudes. Thus, hiring disabled workers can be promoted by the organization as an additional diversity initiative. As we confirm in our own research, this sort of action can provide valuable mentorship opportunities for disabled students and normalizes disability.

Oud (forthcoming) offers an interesting snapshot of the successes and challenges of a group of Canadian academic librarians that are disabled. In particular, Oud reminds us that disability includes a diverse array of conditions, and that disabled people can be successful library employees. This was confirmed by her survey.

The Americans with Disabilities Act

Wilhelmus and Wilhelmus (1997) outlined the legal requirements for reasonable accommodations created by the Americans with Disabilities Act (ADA). The ADA is a “comprehensive civil rights statute” (2). Within the context of professional work as a librarian, the “essential functions of a library position” (4) should be considered. The ADA requires “reasonable accommodations” (4) to be made for people who are self-identified as disabled, thus making it possible for a person with disabilities to do their job.

The ADA is known as a law that is moved forward by citizen activism. It is complaint driven. The most common complaints toward libraries have been about digital accessibility. Many libraries have been pushed by civil-rights actions to make their web presence more accessible to the visually impaired (Walker and Keenan 2015). This is often where the conversation about accessibility begins in libraries. Under the influence of the ADA, a conversation has begun in the library literature about the importance of access to librarianship and educating us all regarding the needs of the disabled population. Gunde (1991, 806) uses strong words—“Hypocrisy . . . which officially preaches outreach but more often prac-

tices exclusion”—to describe libraries who have not undertaken to make their material available to all students. The questions of access and social justice are connected to our study, but are not the specific focus (Kumbier and Starkey 2016).

Passing

The issue of passing comes up in our research study in two places. Some people, like one of the coauthors, attempted to “pass” as nondisabled when they were younger. This can be problematic because it is a difficult journey when the problem can no longer be ignored (Brown 2018). Passing also came up among librarians who are dealing with “invisible disabilities.” Invisible disabilities are described as such because they’re not readily apparent to others. They include a wide variety of conditions, including cognitive challenges, chronic illness, mental disorders, and sensory disorders (Santuzzi et al. 2014). The literature doesn’t always include this factor in discussions of passing and disability.

Brune and Wilson (2013, 2) remind us that disability and normality are not a dichotomy. It’s not a question of either disabled or normal; it’s a fluid arc. Passing is sometimes about self-deception and stigma (Wilson 2013, 20–21). This certainly can be true. A person who transitions out of passing has usually come closer to self-understanding.

Todoroff and Lewis (1992) remind us that passing is also about fear of discrimination, as well as fear of other people’s reactions. A lot of clarity about the relationship between the disabled and the able-bodied is deeply based in aging and with it the fear of death (Todoroff and Lewis, 1992, 34). Observing the disabled, we might notice what Siebers (2017, 324) observed; that is, “Disabled people who pass for able-bodied are neither cowards, cheats, nor con artists but skillful interpreters of the world from whom we all might learn.”

A review of the literature on passing “revealed the subjectivity of identity, and the messiness of all socially constructed categories of human difference” (Rembis 2013, 113). It would be interesting elsewhere to explore the parallels between disability studies, feminism, and queer studies, because each discipline has wrestled with the subjectivity of identity and the messiness of the ego.

Invisible Disabilities

A decision was made by the authors to address invisible disabilities as part of our research. This came from a desire to deal with a range of challenges, and to honor our colleagues whose brains or thought processes work differently, because we felt we had common ground. That being said, the literature-review work mostly focused on physical impairment, and thus the idea of invisible disabilities turned up in tandem with physical impairment.

Susan Wendell (1996, 37–38) offers specific observations on “the pace of life” being disabling. She writes very powerfully about her experiences with a chronic illness. The problems with the pace of life connect with fatigue, which is an overarching characteristic that affected many of the respondents that we spoke with.

METHODOLOGY

The authors sent recruitment notices to a range of listservs aimed at disabled librarians and academics and recruited helpers from different types of libraries. Currently our dataset is running at just over fifty participants. Respondents include librarians who work in many different types of libraries and with many different job titles. There does not appear to be any typical library job for a disabled librarian. One informant came from Australia, and at least one from Canada, but the data mostly reflect conditions in the United States.

There were two phases to this research design. Everybody was asked to answer a quantitative survey. Survey participants were then offered the opportunity to participate in an interview in order to further explore the issues raised in the survey. Interviews were recorded using Zoom so that the authors could reflect on what was said. None of the excerpts discussed below are attributed, to preserve the anonymity of our informants.

RESULTS

Major Challenges

Our survey allowed people to self-identify with multiple issues (see table 1). Many of those with clear mobility issues had additional problems. Of these additional difficulties, fatigue came up repeatedly during the interviews. Every type of fatigue, from the fatigue that is the result of navigating with a mobility disorder, to the exhaustion caused by trying to successfully navigate a neurotypical world, was specified. Negotiating a workplace with any form of disability can be exhausting.

Table 1. Types of disabilities faced by the respondents (offering the option of multiple answers)

| Disability | Percentages |
|---------------|-------------|
| Mobility | 58.5 |
| Energy Level | 47.2 |
| Psychological | 37.7 |
| Sensory | 28.3 |
| Cognitive | 24.5 |
| Learning | 17 |

Visibility

The authors wanted to understand how visible the respondents felt vis-à-vis their disability (see Appendix A, question 2). What jumped out is that 37.5 percent of our respondents felt that their “challenges” were invisible. This may be because of the multiple concerns reported in response to survey question 1 (see “Major Challenges,” above), specifically energy level, sensory, cognitive, learning, and psychological issues.

This survey also included librarians who identify their disabilities as being invisible. These disabilities may include mental-health issues, as well as learning and cognitive differences. This article is a portrait of a community with a wide range of problems and needs. Just under half of our respondents reported being persons with mental-health disabilities. We contacted librarians for interviews who had a range of disabilities. About half of them disclosed having a visible disability, although most of the people with mobility problems also connected with having emotional and/or cognitive issues as well. The range and variety of stories the interviewees told was impressive.

Reasonable Accommodations

Many of our respondents reported requesting reasonable accommodations on the job or in library school (64.2 percent). This stresses the value of the Americans with Disabilities Act (see above). The authors conclude that it is extremely important to continue to work on making conferences accessible to all—58.5 percent reported needing support at conferences. There are disabilities activists within ALA that have been working hard to make the semiannual conferences of ALA more accessible (Brown, personal experience).

While anyone can request reasonable accommodations based upon their disability, the authors discovered that respondents with progressive mobility issues are the most comfortable seeking reasonable accommodations. This is especially true as their disability progressed; when you can no longer hide, then willingness to self-identify and seek accommodations is unavoidable.

The Impact in the Job Market

This question (see Appendix A, question 7) had a pretty high response rate, which indicates to the authors that this concern is widespread within the community. Just over half of the people answering our survey, when asked about whether their disability affected their career, agreed with the statement “Not explicit[ly], but I have my suspicions.” This is, of course, subjective. One of the long-term goals of opening up the conversation about disabled librarians is to help hiring managers be aware of the value of focusing on ability, rather than concentrating on disability.

Commitment

Several of the questions in our survey tried to get at the librarian's drive and their commitment. In our initial survey, 64.2 percent reported being completely exhausted at the end of the workday. One respondent reported a life divided between self-care and work. Many respondents found this issue hard to quantify. Most of our respondents reported putting in hours outside of regular office hours, just to keep up with their required work.

We did explore the issue of work ethic in our interviews. In all of the interviews, we heard about working longer and harder as a compensating behavior. This is reflected widely in informal conversations in the disabled community (Brown, personal experience). The need to prove oneself is universal. It is not unique to disabled individuals. The reasons given for this behavior were "[trying to] catch up with my peers" or being a "type A personality, overworking."

How Visible Are We in the World?

Passing is a documented part of the disabled experience (see above). A disability does not have to be visible to make it difficult to navigate in our able-bodied, neurotypical world. Many of our respondents (61.5 percent) understood "passing to be relevant to their journey" (see Appendix A, question 11). About twenty-five people (out of fifty-four) indicated that they currently "pass." Based on our own experiences with visible mobility issues, these twenty-five might represent the portion of our group with invisible cognitive, sensory, psychological, or learning disabilities.

Passing was discussed in all of the interviews (see Appendix B). People "pass" because it can be easier to try to "fake it," rather than having to constantly explain yourself. The interviewees stated that if one has an "invisible disability," constantly explaining your disability is exhausting. However, passing for a nondisabled individual is a difficult choice, because faking also hurts the individual, as has already been discussed above in the literature review.

Allies and Mentors

Many of our respondents (over 60 percent) declared that allies and mentors were very important in their professional lives. The value of community was discussed during the interviews. Most people felt that having a community dramatically increases the quality of life. Networks within the disability community provide mentors and increased self-understanding and self-acceptance. Those respondents who are part of an academic institution felt that a disabled-students club or a gathering of disabled faculty can provide support, guidance, and encouragement.

A manager who has had previous contact with the disabled community (or is a member of the disabled community) is deeply appreciated by dis-

abled librarians. Just as managers can become mentors of new librarians, there are managers who have stepped up to mentor disabled librarians.

Terminology

This project brought forward people who had a whole range of experiences. Terminology was explored during the interviews (see Appendix B). Preferred terminology tended to be specific to the disability the respondent was dealing with. What was most striking to the interviewer were the things that were named as offensive. The following is an abbreviated list of terms that were found to be offensive:

- “Any language that suggests I am not a whole person anymore”
- “Broken brain”
- “Person bound to a wheelchair”
- “Crippled”
- “Don’t use clinical terms unless you are speaking clinically.”
- “Puzzle piece” (Implying that people with autism are incomplete)

Social Dynamics

Social dynamics can be a truly mixed bag. The issues that come forward depend on the nature of the disability. Many of the respondents were very frank about their disability with supervisors and colleagues, but these tended to mostly be people with mobility issues.

Several of the interviews were with autistic people. When social skills have been difficult to learn, job interviews are a big boundary. There is a complex challenge buried in the issue of social dynamics if you have an invisible disability. Anxiety is definitely an issue for people with communication issues. For autistic librarians, existing in an able-bodied neurotypical world is exhausting. Exhaustion can also get in the way of communication and thus contributes to negative social dynamics for people with a wide range of disabilities.

Role Models

The ability to serve as a role model is one of the benefits of “coming out” in our libraries as disabled. This ability to serve as a role model is a major difference between those who have “come out” and those individuals (mostly with invisible disabilities) who are still passing. The people who responded found that being a role model meant the following:

- “Breaking down ableist thinking”
- “Becoming a teacher of disability consciousness”
- Practicing “self-advocacy”

The authors have found that willingness to become an advocate produces a huge boost in self-acceptance. We heard from interviewees many times about the journey to self-acceptance.

A New Normal

The authors found that most of the librarians interviewed felt they were growing in terms of self-understanding. Some had decided to self-identify as a member of the disabled community while they were college students. Some had received diagnoses of invisible disabilities as adults. Receiving a diagnosis is sometimes described as a huge relief. Often a diagnosis brings with it a community and answers many questions. Nobody likes to struggle alone.

Under the heading of “A New Normal,” it’s worth acknowledging that some are aging with physical impairments. This will lead to something that one informant described as a “grieving process.” Many people have to make ongoing adjustments as their bodies change and offer new challenges. This is a process that is similar to able-bodied aging but is magnified by the stresses of disability.

There are also librarians who have acquired a disability through accidental injuries or chronic illnesses. Some have a degenerative condition that may have taken a long time to evolve. Some are newcomers to the disabled community, making the journey toward a new normal. This is one of the unique facts about the disabled community: it acquires new members every day.

What Do We Want Our Managers to Know?

The best situations include having supervisors who understand the problems of staff who have disabilities. A very important theme that came up in the interviews is reflected in Rousso’s book *Don’t Call Me Inspirational* (2013). None of us set out to be inspirational. We are simply coping with our reality, just as our able-bodied colleagues are doing.

To the question, “What do you want your manager to know?” a couple of comments are worth noting:

- “That I am a real asset”
- “I need things in writing.”
- “My challenges don’t define me.”
- “None of us want pity or condescension. We want to be seen as competent, whole people.”
- “My world isn’t your world.”

Written communication can be useful for people who have a wide range of challenges. It provides a record that can be referred back to. It provides clarity to those who struggle with verbal communication.

One of the ways that the environment can become disabling is during winter weather. Be aware of those who rely upon walking, rolling, and mass transit. If it is necessary to stay home because it’s treacherous out there, please recognize that a disabled person would rather be at work. There are many gifted librarians out there who don’t drive. The authors are for-

tunate to be based in New York City, which has a wide-ranging mass-transit system that runs around the clock. Mass-transit schedules should take into account professionals with variable schedules.

Is There Any Value in Being Disabled?

The authors spoke with interviewees about moments when being disabled impacts their job (see Appendix B). Many reflected on being given the gift of empathy. Because disabled librarians struggle, they understand the struggles of their patrons. Many spoke about working to make the world a better place. This was particularly true in cases where the respondent was relatively stable in their disability and their coping strategies.

DISCUSSION

The respondents in this survey were self-chosen. The article's authors also had experiences with some "disabled" librarians who reported not feeling "disabled enough" to participate in this survey. This comes back to the idea that disability is at least partially socially constructed. While there are some who may appear disabled to the outsider, some of them have not accepted that label and thus did not want to be part of this study. This meant that we only had a small group of librarians to work with. So this instrument does not reflect a generalizable statistical portrait of all librarians.

The interviews for this article highlighted differences between being physically disabled, having sensory impairments, and functioning with cognitive, behavioral issues. However, each interview found common ground, as everyone we spoke with is functioning with a disability. There are striking variations in the need to self-identify, the appreciation of self-advocacy, and the level of social and communication challenges. The variations are not absolute according to the type of disability but nonetheless were very striking.

The journey toward self-acceptance was something the interviewees spoke a lot about. Many respondents reflected on the power of self-acceptance and the value of self-identifying as a disabled person, along with the power of self-advocacy. To ask for accommodations is a risk, and it takes courage. Depending on the situation, and the disability, not everybody is able to self-identify comfortably in spite of the protections of the ADA.

Because of the author's experiences, we were eager to talk about work ethic. If there is one issue that was repeated in many of the interviews, it was commitment/work ethic, along with the need to keep up with able-bodied colleagues (see Appendix B). Many people we spoke with had an awareness of sometimes working slowly, and so making up for it with long hours. Some reflected on not having much life beyond work and self-care. This agrees with our personal experience. As one of our interviewees observed about new librarians with disabilities: "If they have made it this far, they are rock stars!"

The authors want to honor each of the people in our dataset. They are succeeding with a disability that has become a source of empathy and strength. To hiring managers who encounter people with functional variations, consider seriously the rock-star factor. We are mostly all driven people.

CONCLUSION

When we began this research project, we were not aware that any other research had been done or was being done on disabled librarians. As described in the introduction, we felt very strongly about the need to do this research in order to claim our space within librarianship. Two major limitations of this study are that it is both self-reported and only covers a small sample of all disabled librarians out there. We have no intention of stating that this is a complete picture; rather, it is a beginning.

Future Action Steps

The authors both have mobility impairments. The interviews were an opportunity to begin to understand the world of colleagues who deal with other kinds of disabilities. There is a need to further explore the impact of invisible disabilities in the library world. One question that could be explored in the future is whether there is any awareness work that can be done that will make it easier for neurodiverse individuals who struggle with communication skills to more easily secure jobs?

Changing the library-school curriculum was an apparent need expressed in one of our interviews. Library-school students need to be given disability-awareness training, in tandem with other kinds of diversity training. Particularly, as our society continues to age, disability-awareness training is radically important.

A number of the interviews appeared to demonstrate the impact of the ADA, and how it affected people during library school. The next phase of this research should address, as part of the survey, the impact of the ADA, especially among new librarians, and how it affects their ability to succeed during their training.

We also have an interest in addressing intersectionality. We did not, in our survey, address issues of gender, race, or other kinds of variances. We have come to understand that disability does not stand alone and often occurs intertwined with other issues that impact how people are perceived and accepted.

The authors would like to explore building community around disabled librarians. One immediate takeaway from this research was the discovery of other disabled librarians on a similar career path who shared a disability with one of the coauthors. We also heard from many librarians about the power of community.

We would like to address the issue of increasing the representation

of people with disabilities within librarianship. To help with this, the authors are interested in seeing the American Library Association restart the Century Scholarship Program, which provided some support for disabled library-school students (ALA, n.d.).

GRATITUDE

This project has been an opportunity to have conversations with some exceptional people. The authors are grateful to each person who was willing to share with them.

APPENDIX A: SURVEY QUESTIONS—WRITTEN QUESTIONS

Part 1: A widely distributed quantitative survey

I. Primary diagnosis

1. Please check off any categories that apply

- Mobility
- Energy level
- Sensory
- Cognitive
- Learning
- Psychological

| | | | | | |
|--|-----------|-----------------------|-------------------|------------------|-------------------|
| | Invisible | Occasional challenges | Weekly challenges | Daily challenges | Constant presence |
| 2. How visible or invisible is your challenge? | 0 | 1 | 2 | 3 | 4 |

What parts are most visible, and what parts are invisible?

| | |
|-----------------|-------------------|
| Visible factors | Invisible factors |
| • Mobility | • Mobility |
| • Energy level | • Energy level |
| • Sensory | • Sensory |
| • Cognitive | • Cognitive |
| • Learning | • Learning |
| • Psychological | • Psychological |

3. Do you require reasonable accommodations on the job or in library school?

Yes / No

4. Do you need or desire reasonable accommodations at conferences?
Yes / No

5. What was the impact of your challenge in the job market?

II. Work Ethic

1. What percentage of your total energy are you devoting to your job / career?

2. How many hours do you put in outside your office?

3. How is your energy level at the end of the workday?

4. Does the term “passing” have any relevance in your journey?
Yes / No

5. Do you currently pass?
Yes / No

6. How important are allies and mentors in your workplace?

- Very important
- Somewhat important
- Only slightly important
- Not important

In your professional life?

- Very important
- Somewhat important
- Only slightly important
- Not important

7. How important are allies and mentors beyond the workplace?

- Very important
- Somewhat important
- Only slightly important
- Not important

8. Are you willing to be interviewed for this project?

- Yes
- No

If you are willing to be interviewed, please give us a telephone number, and the best time to call.

Interviews will be transcribed and made anonymous.

APPENDIX B: SURVEY QUESTIONS—ORAL INTERVIEW QUESTIONS

Part 2: Interviews

1. Do you have a visible or an invisible disability?
2. How do you describe yourself?
3. How have social dynamics impacted your life?
4. How have social dynamics impacted your career?
5. As a disabled person, is there any terminology that you prefer?
6. As a disabled person, is there any terminology that offends you?
7. Describe your work ethic.
8. How has job performance been impacted by your disabilities?
9. How do/did you present your challenges to your supervisor?
10. How do/did you present your challenges to your broader working community (campus, library system, colleagues, etc.)?
11. What do you want your manager to know? In an ideal world, what would you do differently vis-à-vis your manager?
12. How important are allies and mentors in your workplace?
 - 12a. How important are allies and mentors in your professional life?
 - 12b. How important are allies and mentors beyond the workplace?
13. Does the term “passing” have any relevance in your life as a disabled person?
 - 13a. If passing has relevance, how do you understand it?
 - 13b. Do you currently pass?
 - 13c. Was there a moment when you could no longer pass?
14. Do your disabilities lead to communication problems?
15. Are you a role model for your patrons?
 - 15b. Are you a role model in your life?
16. Have there been moments when having a disability add to your job?
17. How has your disability evolved?
 - 17b. Do you have a “new normal”?
 - 17c. Have you had to make adjustments in career expectations because of your disability?

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