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# Hidden Barriers: The Experience of Academic Librarians and Archivists with Invisible Illnesses and/or Disabilities

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This study documents the experience of, and identifies professional barriers for, academic librarians and archivists with invisible illnesses and/or disabilities. Results from a survey of MLIS-holding individuals in academic positions indicate that invisible illness or disability often impacts the ability to succeed at work, but many are reluctant to disclose or request accommodations to alleviate those disparities. Respondents reported barriers including professional repercussions for disclosure, difficulty during the hiring process, stigma from supervisors and colleagues after requesting accommodations, and an overall lack of understanding about invisible illness and disability in the profession.

#### Introduction

The library profession, and in particular academic librarianship, has sought to make the field more inclusive and diverse for much of the last twenty years. Despite this commitment, there has been little done to make academic librarianship more accessible to workers with disabilities. In the Association of College and Research Libraries' 2012 Diversity Standards: Cultural Competency for Academic Libraries, the group refers to librarians with disabilities only once: "Diversity is one of ALA's five key action areas to ensure high-quality library services to all constituents. Within that mission is the need to recruit underrepresented groups and individuals with disabilities to the profession." This statement is also the only mention of disability on ACRL's Equity, Diversity, and Inclusion LibGuide outside of a few linked articles. Furthermore, the only division of the American Library Association to have a statement about library workers with disabilities has been

disbanded.<sup>2</sup> Despite ALA and ACRL's commitment to diversity, equity, and inclusion, they provide no structured support for librarians belonging to one of the largest marginalized identities in the country.<sup>3</sup> These shortfalls of our professional organizations have left library workers with chronic illnesses and disabilities few resources to help navigate the inaccessibility of the field, and minimal professional discourse about their experiences.

In ALA's 2017 demographic study of about 38,000 members, 2.91 percent of respondents answered yes to the question, "Do you have a disability?" This is up from 2.8 percent in the 2014 study.<sup>4</sup> However, the demographic data from ALA may not match the actual lived experience of library workers with physical or psychological impairments or chronic illnesses that qualify as a disability under the Americans with Disabilities Act (ADA). For example, in a survey of more than 500 academic librarians with mental illness, only 8 percent of respondents considered their mental illness a disability. This gap in selfidentification could cause ALA's demographic information to miss library workers living with illnesses that impact their daily life. In addition, the ALA study only includes members and therefore does not encompass the entire profession. Beyond this data, research about the experience of librarians with disabilities has only emerged within the last five years in LIS literature. Common barriers for disabled librarians are beginning to be documented as we develop a basic understanding of the inaccessibility of academic librarianship. In order to fully address these barriers, we must investigate the unique experiences of librarians with different types of disabilities, including those considered "invisible."

Throughout this article and the study it describes, we use "invisible" (in reference to illness and/or disability) as an adapted definition from the Invisible Disabilities Association: "An invisible disability is a physical, mental or neurological condition that is not visible from the outside, yet can limit or challenge a person's movement, senses, or activities." Though it was the term used most frequently in the initial literature review and this study's development, using invisible versus visible may be problematic for people with disabilities. Margaret Price et al. found that the invisibility metaphor places an additional burden on the person with disabilities by implying it is their responsibility to make themselves visible. Alternatively, the term non-apparent places responsibility on others to recognize an individual's disability. Like most identifying terminology, the preference of the individua person should be paramount when discussing disability. We suggest non-apparent or not-readily-apparent as alternatives to invisible. This article will use invisible, non-apparent, and/or hidden to signify that a person's illness or disability cannot be easily identified by other people.

This research study intends to capture the experiences of academic librarians, including archivists, living with invisible or non-apparent illnesses and/or disabilities.

The study has two primary objectives:

1. To identify barriers facing individuals with invisible illness and disability who are degreed LIS professionals working in academic libraries

2. To determine ways academic libraries and the LIS profession can be more inclusive and accessible to those with invisible illness and disability

#### Literature Review

#### Invisible Illness and Disability

To understand disability within LIS framing, we recommend Alana Kumbier and Julia Starkey's definition of disability as an "inherently relational, social matter; it is something that happens, over and over, in interactions among people." It is an experience that is "shaped by social, cultural, historic, political, and economic factors...[that] impact people's lived experience of impairment." Unfortunately, most discussion of disability within LIS has been far more limited than Kumbier and Starkey's comprehensive definition of lived experience. The majority of LIS literature focuses on patron access through building compliance to the ADA and website accessibility. This narrow perception creates an insufficient understanding of disability in librarianship, as being disabled is a far more diverse experience than using a mobility aid or experiencing vision loss. It extends to many impairments that are not visibly apparent to others, including but not limited to physical illness, mental illness, and learning and developmental disabilities.

Having a non-apparent illness or disability presents unique challenges for academic library workers. As detailed by N. Anne Davis, "When individuals are not 'seen' as disabled, it can be more difficult for them to secure the assistance or accommodation they need to function effectively. Because they are not identified as disabled, those whose disabilities are invisible must often bear the burden of securing the assistance they require." 10 Librarians with invisible illnesses and/or disabilities must navigate the deeply personal experience of deciding when, how, and to whom to disclose their conditions. Invisibly disabled workers often choose not to disclose for fear of not being believed or experiencing repercussions from supervisors and coworkers. 11 This is especially true for individuals with commonly stigmatized conditions, such as mental illness or chronic pain, and for those who do not personally identify as disabled. 12 In addition, when disability intersects with other marginalized identities, disclosure is even more fraught. A person of color, for example, who may already experience racism in the workplace, would need to weigh the additional ableist discrimination that could accompany disclosure. 13 In a field with well-documented racial disparities in our workforce, academic librarians of color could be at particular risk for repercussions when navigating disclosure. However, disclosure in some form is required to receive accommodations under the Americans with

Disabilities Act.<sup>14</sup> Workers who do not feel safe disclosing or going through the accommodations process therefore have little recourse to adjust their work environment. This barrier could lead to decreased workplace performance or worsened health conditions over time.<sup>15</sup>

When evaluating academic librarianship for equity and inclusion, we must consider how concerns regarding disclosure, workplace culture, and accommodations found in the larger workplace research are present for librarians with non-apparent illnesses or disabilities. Unfortunately, the unique accessibility concerns for invisibly disabled library workers have not been extensively examined by the profession.

#### Disability in LIS Literature

The majority of library literature on disability focuses on serving patrons with disabilities and ensuring that library buildings are accessible. In a content analysis of disability and accessibility in LIS literature, Heather Hill found that of the 198 articles examined, only 35 percent were research articles, and that much of the literature focused on presenting problems and recommending solutions. Thirty-six percent of those research articles included people with disabilities in information seeking or accessibility testing roles. None had authors that self-identified as disabled, and no theme emerged about library workers with disabilities. 16 Similarly, Kumbier and Starkey found that most LIS literature and documentation on access, including diversity initiatives, use a "tick-box' framework" to treat access or disability issues as individual problems to be solved instead of systemic inequalities that prevent librarianship from realizing our professional values of access and equity.<sup>17</sup> Finally, in a quasi-systematic review published after this study ended, Amelia Gibson, Kristen Bowen, and Dana Hanson found 820 pieces of LIS literature on disability published between 1978 and 2018, and studied a sample size of 282 articles. From that sample, they found that the majority (80.7%) of the original research studies focused on technology and 79 percent of the sample discussed disability as primarily a physical characteristic or using the medical model. 18 Few articles in their study recognized disability as a social construct or the intersectionality of disability and other marginalized identities. Like the two reviews discussed above, this one concluded that the literature "suggests an unprioritized and short-sighted understanding of disability and much work to do." 19

For this study, we reviewed the limited number of articles written about the experience of library workers with a disability, including some that examine the unique experience of library workers with invisible illnesses and/or disabilities. These articles represent an emerging field within LIS literature. The two earliest articles were from outside of North America and discuss disability in academic libraries through Australian and Irish law, respectively. The articles from North America were published starting in 2013; they are a combination of research articles, reflections on the field, and personal experience. In an ACRL Conference Session, Kiyomi Deards discusses what appears to be the first survey

about the workplace experiences of academic librarians with health conditions. Deards used twenty-five open-ended questions primarily regarding health and workplace issues but received a small sample size of only seventeen responses. The survey was not complete at the time of the conference presentation, and there do not appear to be additional publications about it.<sup>21</sup>

The first identified research articles about disabled library workers did not appear until 2018. Joanne Oud conducted a survey of academic librarians in Canada to measure job satisfaction and perceptions of librarians with disabilities. Of the 268 respondents, 14 percent self-identified as having a disability, and 72 percent of those individuals reported having an invisible disability. In a few disability-specific survey questions, respondents noted an overall distrust in the accommodations process; 68 percent said they had not requested any, fear of the impact on their jobs being the primary reason. Overall, the librarians with disabilities reported similar levels of job satisfaction as other respondents, but they did score their institutions lower on diversity and accessibility than non-disabled respondents. Significantly, respondents who reported they were managers had a higher satisfaction with the diversity and accessibility in their institutions than respondents who were not managers. Since very few of the librarians with disabilities also reported being managers, this suggests a disconnect between manager perceptions about accessibility in the workplace and that of library workers with disabilities.<sup>22</sup> Oud interviewed ten of the respondents with disabilities to gather more information about their experiences in the workplace and explored that qualitative work in a later article. Nine of the ten interviewees reported invisible disabilities and major barriers corresponding to a lack of understanding about disability within the profession, the most common of which were adjusting to colleague and supervisor discomfort, reluctance to disclose or discuss the disability, and reluctance to request ADA accommodation.<sup>23</sup> Most respondents indicated that more open discussion and awareness about the diversity of disability in the workplace would improve their work environments.<sup>24</sup> In addition to Oud's work, Robin Brown and Scott Scheidlower published the results of a quantitative and qualitative study of librarians with disabilities. Around fifty people self-identifying as disabled completed a survey, and the authors interviewed a portion of the respondents. They included responses from librarians with a variety of disabilities on topics such as identity, work ethic, and community. Notably, roughly 38 percent of respondents reported "challenges" that were invisible and 64 percent had requested accommodations.<sup>25</sup> In another survey, Erin Burns and Kristin Green focused specifically on the stigma librarians with mental illness face in the profession, adapting Michael King et al.'s forty-five question survey measuring mental health stigma to be librarianship-specific.<sup>26</sup> They had over 500 respondents and found that potential stigma was a large barrier to disclosing their mental illness in the workplace. Significantly, only 8 percent of respondents considered their mental illness a disability.<sup>27</sup> The most recent study of librarians with disabilities is Kelsey George's book chapter, published after our survey was completed. In a survey of ninety-nine self-identifying library

workers with disability and/or chronic illness, George found that most (82%) reported disclosing their disability or illness in some way in the workplace, and fifty-six of the respondents reported experiencing ableist microaggressions from colleagues or patrons.<sup>28</sup>

Reflections on the profession and personal experiences appear in the LIS literature starting with Jessica Schomberg's 2018 book chapter that explores Critical Disabilities Studies and its implications for improving inclusion of workers with disabilities in libraries.<sup>29</sup> Schomberg, along with Wendy Highby, later published a book titled *Beyond* Accommodation: Creating an Inclusive Workplace for Disabled Librarians. This book combines theory with the authors' experiences and that of interviewees to explain the current state of disability inclusion in librarianship and present ways to improve the accessibility of the field. 30 Experience and theory is also blended in a 2019 Library Trends issue on disability; Teneka Williams and Asha Haggod reflected on the state of disability in diversity work, J Pionke detailed the barriers he faced when requesting accommodations, Gina Schlesselman-Tarango explores her experience with infertility and its accompanying grief, and Christine Moeller examines how precarity and ableism in academia harms librarians with disabilities.<sup>31</sup> In one of the few writings specifically on invisible disability and librarianship, Samantha Cook and Kristina Clement explain the unique challenges faced by people with invisible disabilities in the workplace and how libraries can best support them.<sup>32</sup>

Lastly, two columns specifically addressed barriers to the hiring process for librarians with disabilities. Anne Ford wrote about barriers during the hiring process for people of color, LGBTQIA librarians, and librarians with invisible disabilities in American Libraries. The section on invisible disabilities included interviews with two librarians self-identifying as disabled, both of whom expressed concern about disclosure of their disability during the job search process. Elizabeth Leonard provided a brief literature review on the barriers to hiring people with disabilities and improving diversity in librarianship. This column concludes with recommendations for employers looking to create more inclusive hiring practices. 34

Overall, it appears that librarianship as a profession is only starting to grasp the impact of disability on the experience of library workers. The current literature on academic librarians and archivists living with disability or illness presents a number of barriers to equitable access to work, including stigma from colleagues, fear of disclosure, and the inaccessibility of the accommodations process. This echoes the larger body of literature on invisible disability in academia, which heavily focuses on the complexity and personal nature of the decision to disclose and request accommodations. The accommodations process itself is also noted in many studies as being difficult to navigate, due to a lack of

clear policies for faculty. Most authors conclude that academia needs to shift to providing readily accessible accommodations and that doing so will benefit all workers.<sup>35</sup>

## Methods

Across both academic and LIS literature, there is clear indication that the field lacks an inclusive and accessible environment for disabled workers. By better understanding how these barriers impact academic library workers specifically, we can move closer to an equitable profession. To build that understanding, we posed three research questions to be answered through a study of academic librarians and archivists living with non-apparent illnesses and/or disabilities:

- 1. How does living with an invisible illness or disability impact the ability of full-time, degreed LIS professionals in academic libraries and archives to do their work?
- 2. How do degreed academic LIS professionals handle disclosure of their invisible illness or disability?
- 3. How do degreed academic LIS professionals face barriers/stigma in the workplace for their invisible illness or disability?

Mixed-methods approaches were used to determine themes and correlations within data. This study implemented a survey with both open-ended and closed questions to address research questions. Quantitative data was collected and analyzed to better understand objective numerical results, while qualitative data was collected and analyzed to provide rich, descriptive responses in which participants could elaborate on their experiences.

#### Respondents

The population for this study comprised academic librarians and archivists with invisible illnesses or hidden disabilities. Respondents self-identified as both being a librarian with a masters degree in library science/studies (MLS, MLIS, MSIS, etc.) and as having an invisible illness or hidden disability. We provided respondents with definitions to ensure consistency and clarity in identification. We adapted and cited definitions of disability, chronic illness, invisible, and accommodations (see appendix A). We differentiated between disability and chronic illness, as not everyone who lives with a chronic illness identifies as being disabled. Sampling frames were selected based on relevant groups and calls for participation sent to ALA and SAA LISTSERVs, including ACRL Universal Accessibility Access Group, ACRL Community and Junior College Libraries (CJCL), ACRL College Libraries Section (CLS), ACRL University Libraries Section (ULS), and SAA's Accessibility and Disability Section. The survey was also shared through snowball sampling on our social media accounts.

#### **Data Collection**

The survey instrument was designed specifically for this research. Questions, phrasing, and terminology were based on extensive consultation of the literature on invisible disability in the workplace as well as our lived experiences as academic librarians with invisible illnesses. The survey was input into Qualtrics and distributed over a four-week period from April 15 to May 15, 2020.

The thirty-question survey employed three sections designed to capture different information in an accessible format (see appendix A). Part 1 was a short demographic section of multiple choice questions to collect background information of respondents. It also included qualifying questions about living with an invisible illness or disability. Part 2 consisted primarily of multiple choice questions about respondents' time in librarianship, including disclosure of illness and/or disability to address the second research question and accommodation requests to address the third research question. Participants could elaborate on answers through two open-ended questions related to describing disclosure and discussing accommodations. Lastly, part 3 used Likert scale questions to examine specific aspects of the academic library workplace to determine potential barriers to the profession. Part 3 was further divided into four subsections: "Hiring Process," "Daily Work Experience," "Professional Development," and "Accommodations." The combination of these subsections provided data for all three research questions.

The survey format was chosen specifically to ensure the survey was minimally taxing for respondents. Individuals who live with invisible disabilities may have limited energy reserves and be unable to respond to lengthy, open-ended questions. We separated part 2 and part 3 to provide consistency in question format and created subsections in part 3 so as not to overwhelm the respondents.

#### Data Analysis

To make sense of qualitative data, four members of the research team coded responses to open-ended questions independently. Rather than using a pre-established codebook, we allowed for codes to emerge organically. These codes were compared to ensure agreement among members of the research team. This triangulation process added to the study's validity. Then, twenty-three agreed-upon codes were collapsed into larger themes that represented broad findings. Representative quotes were presented "in vivo," allowing respondents' words to speak for themselves. Quantitative data was largely analyzed through descriptive statistics.

#### **Ethical Considerations**

Prior to data collection, IRB approval was obtained through the researchers' four individua institutions, with one serving as the overseeing board. The Qualtrics survey opened with an explanation of the study, followed by a consent statement which provided potential respondents with information about the voluntary nature of the study, as well as

measures to ensure confidentiality. Additionally, the study opened with definitions related to invisible disability, which allowed for respondents to clearly understand the language and terms used throughout the survey (see appendix A). No participant names were collected. Respondents could elect to provide email addresses if interested in follow-up interviews; this data was collected in a separate, linked survey that did not connect identifying information with survey responses.

# **Findings**

The findings for this study are presented primarily in the order the questions appeared in the survey. Questions about accommodations, however, were consolidated into one section to best demonstrate respondent experience. A full dataset is linked in appendix B.

## Demographics

The number of responses varied based on the experiences of respondents, but the overall number of responses rate was 359. Fifty-nine respondents were disqualified due to either not working in an academic library or not identifying as having an invisible disability, leaving our primary sample size to be 300. The only required questions were the initial qualifying questions; the remainder of the questions were optional, and respondents could choose to respond or skip different questions based on their experiences.

In part 2, respondents were asked a series of questions related to age, gender, and race/ethnicity, and basic questions pertaining to their employment. The majority of respondents (29%) were ages 29–35, 27.6 percent were 35–45, 16.2 percent were 45–55, and 12.8 percent were 55 and older. White respondents made up 79.5 percent of the total, while 3.3 percent were Black/African American and Hispanic/Latinx, 0.3 percent were Native American and Pacific Islander, 1.1 percent were Asian, and 3.1 percent identified as other.

When asked if they had a chronic illness, 65 percent of respondents selected yes, with 67.1 percent identifying the chronic illness as invisible. When asked if they had one or more disabilities, only 50.7 percent of respondents selected yes, with 57.7 percent identifying their disability as invisible.

In part 2, respondents were then asked two questions about work history. Among the respondents, 24 percent have been working in the LIS profession for five to ten years, 18.4 percent for ten to fifteen years, 16.4 percent for twenty-plus years, 15.9 percent for less than five years, and 9.5 percent for fifteen to twenty years. When asked how long they have been in their current position, 24.8 percent have been working for less than two years, 24.5 percent for two to five years, 18.9 percent for five to ten years, 8.5 percent for ten to fifteen, 4.5 percent for fifteen to twenty years, and 3.3 percent for twenty-plus years

#### Disclosure

In part 2, respondents were asked a series of questions about disclosing their illness and/or disability in the workplace. First, they were asked who they have disclosed their illness or disability to at work. Then, using conditional logic, they were asked when they chose to disclose in each situation. They were given a set of answers to choose from in a check-all-that-apply format, with "other" as an option in every case. Tables 1–8 represent the results from these questions. "Colleagues I consider close friends" was the most frequently selected option for the first question (24.33%), with the majority of responses to its follow-up question being "As I built a personal relationship with colleagues" (51.34%). "When my illness/disability impacted my work" was the most frequently selected answer to the follow-up question for colleagues they work with regularly (36.78%), direct supervisor (38.42%), other library administration (29.41%), library director (31.43%), and open to everyone (26.83%). Lastly, requesting accommodations was the most frequently selected option when disclosing to human resources or a disability office (36.23%).

TABLE 1
Whom have you disclosed your illness and/or disability to at work?

| Field  | Count | Percentage |
|--|-------|------------|
| Colleagues I consider close friends                          | 154   | 24.33%     |
| My direct supervisor (if not library director)               | 125   | 19.75%     |
| Colleagues I work with regularly                             | 113   | 17.85%     |
| Library director   | 53    | 8.37%      |
| I am open about my disability/illness with everyone          | 53    | 8.37%      |
| Human resources/disability office                            | 50    | 7.9%       |
| No one   | 41    | 6.48%      |
| Other library/administrator that I do not report to directly | 21    | 3.32%      |
| Other  | 23    | 3.63%      |
| Total  | 633   |            |

TABLE 2

When did you disclose to colleagues you consider close friends?

| Field | Count | Percentage |
|-------|-------|------------|
|-------|-------|------------|

| As I built a personal relationship with colleagues | 115 | 51.34% |
|--|-----|--------|
| When my illness/disability impacted my work        | 57  | 25.45% |
| Upon receiving a diagnosis or beginning treatment  | 22  | 9.8%   |
| Once I began working                               | 14  | 6.25%  |
| When requesting accommodations                     | 10  | 4.46%  |
| Other  | 6   | 2.68%  |
| During the interview/hiring process                | 0   | 0%     |
| Total  | 224 |        |

TABLE 3
When did you disclose to colleagues you work with regularly?

| Field  | Count | Percentage |
|--|-------|------------|
| When my illness/disability impacted my work        | 64    | 36.78%     |
| As I built a personal relationship with colleagues | 53    | 30.46%     |
| Upon receiving a diagnosis or beginning treatment  | 21    | 12.07%     |
| Once I began working                               | 18    | 10.34%     |
| When requesting accommodations                     | 12    | 6.9%       |
| During the interview/hiring process                | 3     | 1.72%      |
| Other  | 3     | 1.72%      |
| Total  | 174   |            |

**TABLE 4**When did you choose to disclose to your direct supervisor (if not the library director)?

| Field  | Count | Percentage |
|--|-------|------------|
| When my illness/disability impacted my work        | 68    | 38.42%     |
| When requesting accommodations                     | 27    | 15.25%     |
| As I built a personal relationship with colleagues | 25    | 14.12%     |

| Upon receiving a diagnosis or beginning treatment | 24  | 13.56% |
|---|-----|--------|
| Once I began working                              | 22  | 12.43% |
| During the interview/hiring process               | 7   | 3.95%  |
| Other   | 4   | 2.26%  |
| Total   | 177 |        |

TABLE 5

When did you choose to disclose to other library administrators/managers that you do not report to directly?

| Field  | Count | Percentage |
|--|-------|------------|
| When my illness/disability impacted my work        | 10    | 29.41%     |
| As I built a personal relationship with colleagues | 6     | 17.65%     |
| Upon receiving a diagnosis or beginning treatment  | 5     | 14.71%     |
| Once I began working                               | 3     | 8.82%      |
| When requesting accommodations                     | 5     | 14.71%     |
| During the interview/hiring process                | 1     | 2.94%      |
| Other  | 4     | 11.76%     |
| Total  | 34    |            |

**TABLE 6**When did you disclose to the Library Director?

| Field  | Count | Percentage |
|--|-------|------------|
| When my illness/disability impacted my work        | 22    | 31.43%     |
| As I built a personal relationship with colleagues | 11    | 15.71%     |
| Upon receiving a diagnosis or beginning treatment  | 12    | 17.14%     |
| Once I began working                               | 9     | 12.86%     |
| When requesting accommodations                     | 8     | 11.43%     |

**TABLE 6**When did you disclose to the Library Director?

| Field                               | Count | Percentage |
|-------------------------------------|-------|------------|
| During the interview/hiring process | 4     | 5.71%      |
| Other                               | 4     | 5.71%      |
| Total                               | 70    |            |

**TABLE 7**When did you disclose to the Human Resources/Disability office?

| Field  | Count | Percentage |
|--|-------|------------|
| When requesting accommodations                     | 25    | 36.23%     |
| When my illness/disability impacted my work        | 19    | 27.54%     |
| Upon receiving a diagnosis or beginning treatment  | 9     | 13.04%     |
| During the interview/hiring process                | 6     | 8.70&      |
| Once I began working                               | 4     | 5.80%      |
| As I built a personal relationship with colleagues | 3     | 4.35%      |
| Other  | 3     | 4.35%      |
| Total  | 69    |            |

**TABLE 8**If you are open about your disability/illness with everyone, when did you disclose?

| Field  | Count | Percentage |
|--|-------|------------|
| When my illness/disability impacted my work        | 22    | 26.83%     |
| As I built a personal relationship with colleagues | 21    | 25.61%     |
| Once I began working                               | 15    | 18.29%     |
| Upon receiving a diagnosis or beginning treatment  | 10    | 12.20%     |
| When requesting accommodations                     | 9     | 10.98%     |

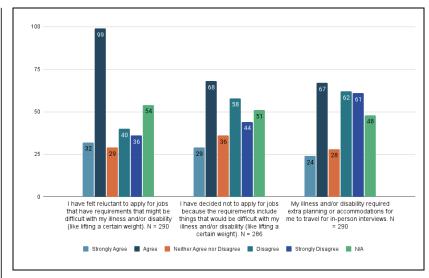
| During the interview/hiring process | 3  | 3.66% |
|-------------------------------------|----|-------|
| Other                               | 2  | 2.44% |
| Total                               | 70 |       |

There were a variety of answers within the "other" section of these questions. One theme presented in the open responses was disclosing when it came up in conversations, such as, "I'm open about it, but only if it comes up" and "After colleagues disclosed their own struggles/initial pursuit of therapy to me." Another theme was disclosing in relation to tenure, with examples such as "After Tenure and well after 20-plus years" and "When my tenure was threatened based on issues related to my illness and disability." Like the last example, some respondents noted feeling forced to disclose due to discrimination, including "When I felt discriminated against & my supervisor was not providing required accomodations [sic]." Finally, a number of respondents discussed selectively disclosing depending on the situation or the type of illness or disability experienced: "I disclose my multiple disabilities differently to different groups"; "I am open about my physical illnesses and disability but I do not disclose my mental illness to anyone except very close colleagues"; and "I am open about my disability (hearing loss) but not about my chronic illnesses."

#### **Hiring Process**

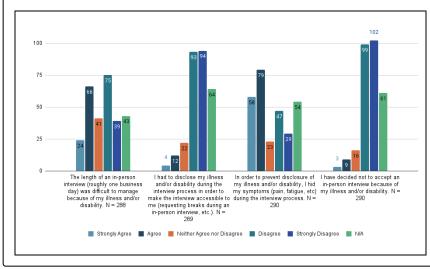
Participants were asked to respond to statements regarding their experiences with the hiring process. They were asked to rank these statements on a five-point Likert scale from "Strongly Agree" to "Strongly Disagree." Respondents could also select "Not Applicable." Figures 1 and 2 below display the data from these questions. Respondents indicated their illness or disability was a major consideration when applying for jobs: 45 percent selected "Strongly Agree" or "Agree" when asked if they were reluctant to apply to positions with inaccessible requirements; 34 percent selected "Strongly Agree" or "Agree" to deciding against applying to positions due to inaccessible requirements. However, the responses were more mixed for the interview process. Even though 47 percent of respondents chose "Strongly Agree" or "Agree" when asked if they hid symptoms during the interview process, 65 percent selected "Strongly Disagree" or "Disagree" to needing to disclose disability to have an accessible interview process, and 69 percent chose "Strongly Disagree" or "Disagree" to rejecting an interview due to inaccessibility.

| FIGURE 1 |  |  |
|----------|--|--|
| Hiring   |  |  |
|          |  |  |





#### Hiring



#### Daily Working Experience

The next section of Likert scale questions asked respondents to respond to a series of statements regarding their daily experience working with a non-apparent illness and/or disability. Figures 3–5 are a series of bar graphs that represent the results. Of particular note from this section is that while only 33 percent of respondents chose "Strongly Agree" or "Agree" to not disclosing because of fear of not being believed, 58 percent did not disclose because it would be too complicated or energy consuming. Positively, 59 percent of respondents reported receiving actionable support from supervisors after disclosing, and only 18 percent reported social repercussions for disclosure. However, 36 percent of respondents selected "Strongly Agree" or "Agree" to facing professional repercussions for disclosing, indicating disclosure was not met overwhelmingly with support.

#### FIGURE 3

#### Disclosure

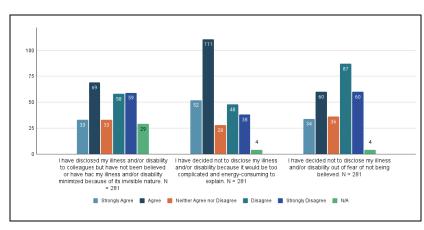
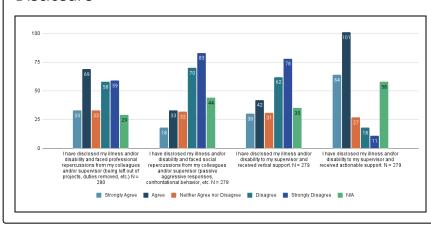


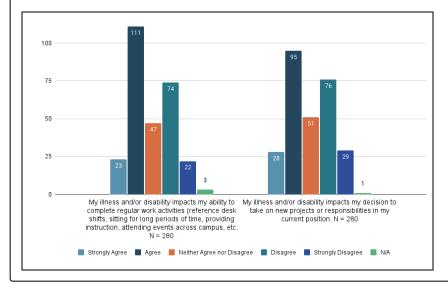
FIGURE 4

#### Disclosure



#### FIGURE 5

#### **Work Duties**



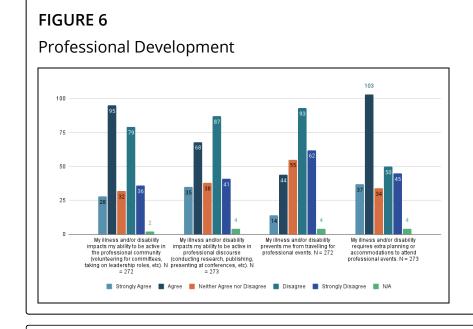
In addition to disclosure, respondents reported the impact of their hidden illness or disability on job duties. Forty-eight percent of respondents selected "Strongly Agree" or

"Agree" when asked if their illness or disability impacted their ability to complete regular work tasks, like reference desk shifts or attending events around campus. Furthermore, a similar number of respondents (44 percent) agreed that their illness or disability impacted their decision to take on new roles or responsibilities within their position.

#### **Professional Development**

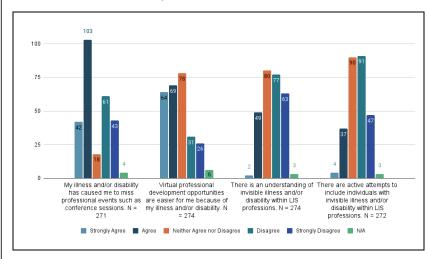
Respondents continued explaining the impact of invisible illness and disability on their lives as LIS professionals by examining their role in their professional development. They responded to statements using a Likert scale, illustrated in figures 6–8. In response to a question inquiring if their illness and/or disability impacts their ability to be active in professional service, 45 percent selected "Strongly Agree" or "Agree," while 41 percent chose "Strongly Disagree" or "Disagree." Comparatively, 38 percent of respondents selected "Strongly Agree" or "Agree" that their illness and/or disability impacted their ability to contribute to professional discourse (publishing, presenting, etc.), but 47 percent chose "Strongly Disagree" or "Disagree" to the same statement. Most significantly, 54 percent indicated they missed professional events due to their illness or disability.

This section also asked about knowledge and support across the profession. Notably, 51 percent chose "Strongly Disagree" or "Disagree" and 29 percent "Neither Agree nor Disagree" when asked if there is an understanding of invisible illness and disability in academic librarianship. Similarly, 51 percent disagreed and 33 percent neither agreed nor disagreed that there are active attempts to include invisibly disabled individuals in the profession. However, there was no clear consensus that current library professional development organizations would be the best avenue to support academic librarians with invisible illness or disability (figure 8).

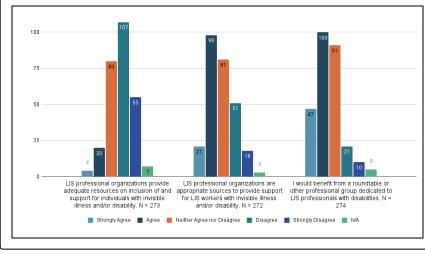


#### FIGURE 7

#### Professional Development





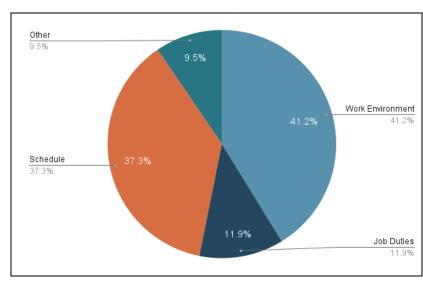


#### **Requesting Accommodations**

In part 2 of the survey, respondents were asked "Have you requested accommodations for your illness and/or disability at your current institution?" Thirty-two percent of respondents selected "Yes," 61 percent selected "No," and 7 percent selected "Unsure." Through conditional logic, respondents who answered "Yes" were then asked if their accommodations had been granted. Eighty-two percent of respondents replied "Yes," 8 percent "No," and 12 percent "Unsure." The prevalence of "Unsure" in the responses indicates a lack of understanding about the accommodations process amongst some respondents. Next, respondents were asked to select all types of accommodations received from the following list: work environment, job duties, work schedule, or other (figure 9).

#### FIGURE 9





Lastly, those who responded "Yes" were asked to elaborate on their experience with the accommodations process in an open-ended text box. Nineteen responses were provided and analyzed. The primary themes that emerged were: (1) changes in job duties, schedule, or work environment, (2) moving from informal to formal accommodations, (3) avoiding disruption, (4) supervisor support or lack of support.

Respondents described changes to their duties, schedules, or working environment based on requesting accommodations. As one said, "I often tire easily, so sometimes I need to work from home more often than my colleagues." Work from home was described by several respondents as a requested accommodation. It should be noted that data collection occurred in May 2020, early in the Covid-19 pandemic, when many employees and employers newly navigated issues with remote work.

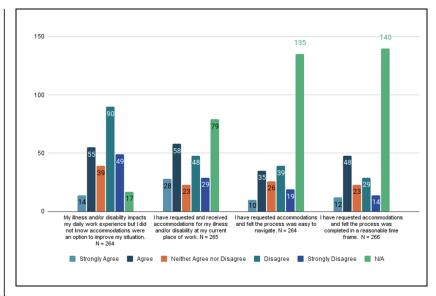
Multiple respondents noted that they had implemented informal accommodations that no longer were enough, which required them to request or file for formal accommodations: "After having an informal accommodation for several years with my first Supervisor, I had to go through the HR process again more recently."

Respondents largely wanted to avoid anything that would disrupt their workplace and were cognizant of this when requesting accommodations. They mentioned wanting to continue to contribute equally, and not wanting to disrupt other employees or workflow. As one participant said, "I always try to schedule appointments when they have the least impact on my work day." Another said that even when working from home, "I am still able to 'pull my weight,' so to speak, so there is usually little disruption." However, librarians also noted that not asking for accommodations could be detrimental. As one librarian, who tried to not "hurt the department" said: "It actually hurt me in the long run because it took longer for me to recover and get back to mostly normal."

Supervisors were mentioned by many respondents, from being very supportive to being unsupportive. Supportive supervisors were described in detail by some; for example: "In all cases my boss has been very accepting and adaptable, working with me to get what I need or approving the changes I am making." However, others described unsupportive supervisors: "My boss yelled at me 'What the hell's your problem? How long do I have to put up with this?"" Finally, some respondents described supervisors who did not grant requested accommodations because activities relating to disability were "deemed essential to the job" regardless of the reality of the work. One respondent whose accommodation was denied explained, ""[The supervisor] has been unsympathetic, unsupportive, and cruel in forcing me to disclose my disability and penalizing me due to my disability in office politics."

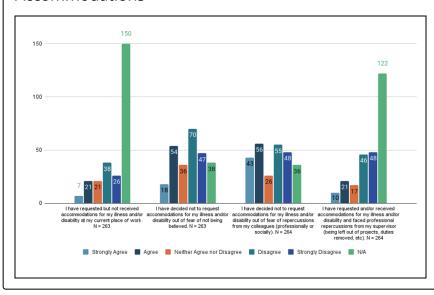
In addition to the initial questions about accommodations, respondents were asked to respond to a series of statements regarding the accommodations process using a Likert scale in Part 3 of the survey (figures 10-12). Even though 53 percent of respondents selected "Strongly Disagree" or "Disagree" when asked if they were unaware that accommodations were an option, "Not Applicable" was overwhelmingly the most common answer throughout the Likert questions about receiving accommodations. This is expected, considering the low percentage of respondents who selected "Yes" when asked if they received accommodations. Also notable from this section were responses related to reasons why respondents did not request accommodations. When asked if they chose not to request accommodations out of fear of not being believed, 44 percent of respondents chose "Strongly Disagree" or "Disagree," with 27 percent choosing "Strongly Agree" or "Agree" (figure 11). Responses were even more closely split when asked if they chose not to request accommodations out of fear of repercussions: 38 percent selected "Strongly Agree" or "Agree" and 39 percent selected "Strongly Disagree" or "Disagree." Though it is unclear what factors may create this close divide amongst respondents, it does indicate that many are reluctant to request accommodations due to potential negative responses from supervisors or colleagues.

| FIGURE 10      |  |  |
|----------------|--|--|
| Accommodations |  |  |



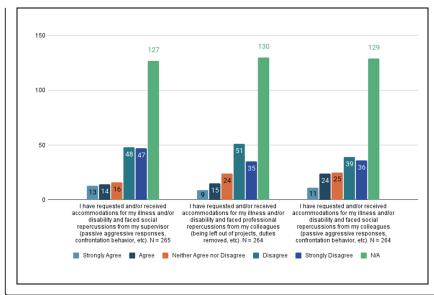
#### FIGURE 11

#### Accommodations



#### FIGURE 12

#### Accommodations



#### Discussion

The results of this study indicate potential barriers to the workplace for academic librarians living with invisible illness and/or disability. Concerns related to disclosure and accommodation are of particular note.

# How does living with an invisible illness or disability impact the ability of full-time, degreed LIS professionals in academic libraries and archives to do their work?

The results of this study demonstrate that invisible illness or disability does impact the ability of many respondents to do their work. More respondents indicated their illness or disability does impact their daily responsibilities and their decisions to take on new projects than did not (figure 5). While this is not a majority of respondents, it is significant enough to acknowledge the relationship between illness and disability and academic LIS work. There was also a gap evident between the number of respondents whose work is impacted by illness and disability, and those who sought accommodations to address those disparities.

When looking more closely at how non-apparent illness or disability impacts the ability of respondents to do their work, one area of note respondents indicated was the hiring process. In order for degreed LIS professionals to do their work in a full-time academic position, they must first navigate the often lengthy academic hiring process. Accessibility of a position was a concern for respondents when applying for full-time work: respondents were often reluctant to apply for positions that may be difficult to fulfill with their illness or disability, and some decided against applying entirely based on inaccessible requirements in a job posting (figure 1). Respondents also noted that their illness and/or disability were considerations throughout the interview process, both through requiring extra planning to travel to interviews and hiding symptoms throughout the interview process (figure 2).

These responses indicate that for some, invisible illness or disability is a determining factor when acquiring a position. This concern, by extension, impacts their ability to successfully work in the field.

Once in their positions, respondents indicated that hidden illness and/or disability impacted their work by hindering participation in professional development to varying degrees. A slight majority indicated illness and disability impacted their ability to be active in professional service, with fewer saying the same for professional discourse, like publishing or presenting (figure 6). The one area that proved more commonly impacted by illness or disability was attendance at professional events: a majority of respondents reported that they have had to miss events due to their illness or disability (figure 7). These responses do not indicate a universal impact on professional development, but they do demonstrate that invisible illness or disability affects the ability of many librarians and archivists to complete service and research. This has particular importance for academic positions, which often require professional participation and research for tenure or advancement. Inaccessibility in our professional discourse therefore may be preventing some disabled academic LIS professionals from doing essential parts of their work.

While there was not overwhelming agreement amongst respondents on how invisible illness and/or disability impacts their ability to do their work, there were clear indicators that it does impact the hiring process, regular job duties, and professional involvement for many librarians and archivists. Further research may shed light on what factors (such as type of position or disability) correlate with the level of impact on work.

# How do degreed academic LIS professionals handle disclosing their invisible illness or disability?

Respondents' hesitancy to disclose their illness and/or disability was identified throughout multiple choice, open-ended, and Likert Scale questions. In terms of when participants disclosed and to whom, the most commonly occurring answer was disclosing to colleagues considered close friends as their relationships developed. The personal nature of these disclosures could be because respondents felt safer in a friendship than a typical work relationship, or because disclosure occurred more naturally outside of the work environment. Besides disclosures to friends, a majority of disclosures occurred most often when it was necessary for job duties. When disclosing to colleagues they work with regularly, direct supervisors, administration, library directors, or everyone generally (57.66 percent of disclosure occurrences reported), participants were most likely to do so when their illness and/or disability impacted their work (tables 1–8). Participants were most likely to disclose to human resources when requesting accommodations (7.9 percent). These results indicate that the majority of respondents may not feel comfortable being open

about their illness and/or disability to their entire workplace community, similar to the findings of George, Price, et al. and Santuzzi et al.<sup>37</sup>

The responses in "Other" for both when and to whom they disclosed provided further nuance about potential hesitancy to disclose. These responses showed that disclosure is often situation-specific, with a number of respondents reporting selective disclosure. They only felt safe disclosing some disabilities and not others, such as physical illness but not mental illness. This was a common occurrence across the literature, notably by Bassler and Burns and Green.<sup>38</sup> In addition, some respondents disclosed when they felt forced: e.g., when tenure was threatened, when a supervisor was being discriminatory. These situational disclosures reinforce the concern that academic librarians and archivists may not be able to openly discuss invisible illness and/or disability in the workplace.

To provide additional context to disclosure, the respondents replied to Likert Scale statements regarding disclosure's impact on everyday work experiences, including fear of not being believed, complications, and more. During the hiring process, respondents did not feel they needed to disclose to receive accessible adjustments like breaks, yet still hid symptoms throughout the process (figure 2). These results demonstrate a distinct hesitancy to disclose during the hiring process, even at the potential detriment to the applicant through inaccessible procedures.

When asked about not disclosing because of a fear of not being believed once in a full-time position, respondents had very mixed experiences, with agreement closely followed with disagreement (figure 3). This aligns somewhat with findings from literature on invisible disability in the workplace, which indicates fear of being believed as the primary reason for not disclosing.<sup>39</sup> Even so, a more common reason for not disclosing in this study was because it would be too complicated and energy-consuming to explain. These results demonstrate that while there is hesitancy to disclose among academic librarians with invisible illnesses and/or disabilities, it may have more to do with an overall lack of understanding about disability in the profession than potential discrimination.

Overall, the findings regarding disclosure indicate that it is difficult for academic librarians and archivists with invisible illnesses and/or disabilities to be open about their experiences in the workplace. The respondents generally did not find disclosure worth the effort or risk in work relationships unless it was necessary for their job duties. In addition, many practiced selective disclosure based on relationship, situation, or type of disability. Further research is needed to better understand the way type of illness or disability impacts disclosure decisions, and how to provide a more secure and knowledgeable workplace where academic librarians can feel comfortable disclosing.

How do degreed academic LIS professionals face barriers/stigma in the workplace for their invisible illness or disability?

The results of this study indicate that while barriers exist for academic librarians and archivists with invisible illness and/or disability, they may not be synonymous with overt stigma in the workplace. For example, withholding disclosure may prevent disabled LIS professionals from receiving accessible accommodations, but there was mixed evidence that respondents had faced stigma as a result of disclosure. Though some respondents noted professional and social repercussions after disclosure, neither were expressed across the majority of responses (figure 4). Positively, respondents also reported receiving actionable support after disclosing to a supervisor and, to a lesser degree, positive verbal responses from supervisors, which was noted as crucial for accessible workplaces in the literature. These results indicate that when librarians did disclose, they were not often faced with stigma in the workplace. However, we cannot discount those who dealt with backlash as a result of disclosure when examining the accessibility of the profession.

Barriers for academic librarians and archivists with invisible illness and/or disability were also evident when considering the interview process. As noted above, they felt relatively negative about applying for jobs that had requirements that might be difficult for someone with an invisible disability, but most respondents still applied for potentially concerning positions (figures 1 and 2). This indicates that while job posting statements like "must be able to lift forty pounds" or other physical requirements can be a barrier to people with invisible disabilities, they do not necessarily stop all individuals from applying. However, the clear apprehension toward these requirements reflects the tension between job duties and the reality of living with an invisible illness or disability. The majority of respondents also did not let their disability stop them from accepting on-campus interviews and did not ask for accommodations during the interviews, with less than 1 percent having requested accommodations. Instead, they suffer quietly through their symptoms, which may impact their performance in the interview. In order to eliminate these potential barriers, the library profession needs to focus on creating more equitable hiring procedures, as supported by Ford and Leonard. 41 These could include removing unnecessary physical requirements from job applications, providing questions in advance of an interview, providing on-campus applicants extra breaks, and offering seating for all presenters, not just the small number who may ask for accommodations. Making the hiring process more accessible to all could help prevent the barriers that are present in academic library hiring but are not being addressed through accommodations.

Beyond the hiring process, there was a clear barrier between the experience of working with an invisible illness and disability and the legal process meant to adapt work duties. Accommodations should provide people with disabilities an equal opportunity to succeed in the workplace, but this study found that they largely are not being offered to academic librarians and archivists. However, this does not mean that respondents' illness or disability did not impact their work in a way that should be alleviated by accommodations. In fact, a majority of respondents agreed that their disability impacted their ability to

complete regular work assignments and their decision to take on new projects. This supports Oud's findings on the reluctance to request accommodations amongst librarians and demonstrates that the process to remove barriers to work for people with disabilities is largely not being provided to academic librarians and archivists. <sup>42</sup> Our results indicate accommodations may not be utilized by invisibly disabled academic librarians because of potential stigma. Some respondents reported fear of not being believed about their illness or disability as a reason not to request. Even more respondents indicated fear of repercussions from colleagues as to why they did not request accommodations. These results correspond with previous studies on accommodations in academia or the workplace more broadly, which demonstrated that employees with invisible disabilities were concerned about or faced stigma from their coworkers for receiving accommodations. <sup>43</sup>

The respondents who did receive accommodations were asked to share whatever they could about the process they experienced. There was evidence of potential stigma for receiving accommodations from both coworkers and supervisors in these responses. A key finding was that librarians who requested accommodations were acutely aware of their coworkers' and organizations' needs and described in detail their efforts to minimize disruption through their accommodations. This consideration was reflected often throughout the responses, yet it was not an overt theme in the initial literature review. This concern reflects awareness that their accommodation may be looked on unfavorably by their coworkers and may correspond to concern about repercussions from colleagues expressed by the respondents who did not request accommodations. It appears respondents may attempt to preempt backlash by factoring colleague concerns into their requests for accommodations, if they request them at all. Broader concerns about accounting for organizational needs in the accommodations process may be due to the unique emotional labor expectations and vocational awe recently documented in LIS literature. 44 Further research should be done to better understand these distinctive concerns of academic librarians and archivists, and to determine if they create a barrier to accessing accommodations.

Relationships with supervisors were also frequently mentioned by respondents when discussing their accommodations experiences, as also noted in Oud's findings. <sup>45</sup> Of the nineteen open-ended responses, seven reported supportive supervisors and three reported unsupportive supervisors. A supportive supervisor will be lauded, while librarians will have an extremely negative opinion of an unsupportive supervisor. The number of supportive supervisors mentioned is encouraging, but the negativity of the unsupportive supervisors still demonstrates a potential barrier in the field for librarians and archivists with invisible disabilities. If even some academic library supervisors are "cruel" and "penalizing" in response to disclosure or accommodations requests, a threat of stigma or backlash will remain present throughout the field.

This study's findings demonstrate that there are not universal barriers or stigma for all academic librarians and archivists living with invisible illness or disability, but they nonetheless exist in our profession. Most evident barriers centered around disclosure and the accommodations process, which is in line with the majority of literature on hidden disability in the workplace. All disabled librarians must feel safe disclosing and receiving accommodations for our field to be truly accessible, since both are vital to achieving an equitable workplace. Disclosure is required in some way in order to receive accommodations. When disabled individuals do not feel supported enough to disclose, they are unable to be accommodated, as discussed by Davis. 46 This creates layers of barriers hindering the success of academic librarians and archivists, as evident from this study's results. Academic librarians and archivists first must find the energy, time, and security to disclose their illness or disability. They must also have a supportive supervisor to support their accommodations requests and not penalize them for asking. They then have to navigate the often difficult process of requesting accommodations, a common concern across the existing literature.<sup>47</sup> Finally, if their request is granted, they must balance the opinions of and repercussions from their coworkers with the needs of their library to ensure they are treated fairly in the workplace. These steps may be too daunting to even attempt for librarians and archivists with disabilities who are already struggling to balance work with symptoms.

The solutions to these barriers may lie in addressing the overall lack of understanding about invisible illness and disability in librarianship. Noted both by our respondents (figures 7 and 8) and in the larger literature review, there are pervasive misconceptions about the diversity of disability and the processes that exist to improve disability inclusion in the workplace. Active support for better workplace understanding is needed to address these barriers and prevent future stigma.

## Limitations

Limitations of this study include the narrow participant pool of MLIS holders working in an academic environment. This leaves out other academic library workers crucial to understanding the full picture of disability in the academic library workspace. In addition, by not asking respondents to identify their type of illness or disability (physical, mental, etc.), our data does not include some of the nuances of stigma surrounding disability. Individuals with mental illnesses may have different experiences or reservations around disclosure and accommodations than those with physical illness. We plan to expand our research following this study to help address these limitations. We will interview a portion of our survey respondents to better understand their experiences and gather more data about how the type of disability impacts workplace barriers. We also hope to reiterate our

survey to a larger group of respondents, including non-MLIS holders in academic libraries and library workers in other areas of the field.

This study used Likert scale questions to learn from academic librarians and archivists about their experiences. However, acquiescence bias, in which participants tend to select a positive response over a negative response, may have led to more selection of "Strongly Agree" and "Agree" than other choices. <sup>48</sup> The study used a mix of positive and negative statements throughout the Likert portion in order to balance out this potential effect, but findings should be interpreted with this knowledge in mind. Furthermore, the choice to primarily use quantitative questions potentially hindered our understanding of the nuances within respondent answers or experiences. Additional qualitative research will be pursued in future work to address some of the resulting gaps in findings.

# Conclusion

Our findings regarding the impact of disability on LIS work, decisions around disclosure, and potential barriers or stigma in the field largely align with studies completed in the LIS literature, higher education, and the workplace at large. As such, we reinforce the recommendations for a more inclusive workplace for individuals with non-apparent disabilities. First and foremost, there needs to be a better understanding of the diversity of disability by non-disabled workers and supervisors to create a more inclusive workplace culture. This can be done through regular accessibility training that aims to improve understanding of the barriers facing library workers with disabilities. Supervisors should also familiarize staff with disability concepts such as inclusive language, disclosure, Universal Design, and accommodations. In addition, professional organizations at state and national levels committed to equity, diversity, and inclusion should include more disability and accessibility-focused topics in their programming, as well as provide resources for creating accessible workplace cultures. As we continue to document the experience of library workers living with invisible illnesses and/or disability, we concurrently work to build a more inclusive profession.

# **APPENDIX A. Survey**

# **Explanation of Study**

From a review of current literature on invisible disability in librarianship, the researchers believe that this study is one of if not the first large-scale surveys to quantify the experience of librarians living with invisible illnesses and/or disabilities. As such, we have decided to keep the first survey attempt relatively small, limiting participants to Masters in Library Science (or equivalent) degree holders who work in academic institutions (either as

librarians or archivists). The participants must also identify as having an invisible illness and/or disability. Our plan is to expand this survey to other library types and professionals if it is successful.

The goal of this study is to better understand the experience of academic LIS professionals working with invisible illness(es) and/or disability in order to examine the accessibility of the profession.

#### **Definitions**

For the purpose of this survey, we will be using the following definitions of these key terms:

- Chronic Illness: A physical, mental, or neurological condition or disease that is persistent, including episodic conditions or those with periods of remission and relapse. It may or may not be treatable or curable (adapted from <u>Vickers, 2000</u> (<a href="https://journals.sagepub.com/doi/10.1177/105413730000800203">https://journals.sagepub.com/doi/10.1177/105413730000800203</a>).
- Disability: A long-term, physical, mental, or neurological impairment that, "in
  interaction with various attitudinal and environmental barriers, hinders ...full and
  effective participation in society on an equal basis with others" (Adapted from <u>United Nations Convention on the Rights of Persons with Disabilities</u>
  (<a href="https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html">https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html</a>), Article I).
- 3. Invisible (in reference to illness and/or disability): An umbrella term encompassing physical, mental, or neurological conditions with primary symptoms that are not visible from the outside or apparent to others. Regardless, these symptoms "limit or challenge a person's movements, senses, or activities" (adapted from the Invisible Disabilities Association). Also referred to as non-visible or hidden.
- 4. Accommodations: A modification to a job or workplace environment that allows a person with a disability to perform essential functions (adapted from the <u>Americans</u> <u>with Disabilities Act (https://www.ada.gov/pubs/adastatute08.htm)</u>).

# 

□ 25 or younger□ 25-35□ 35-45□ 45-55

What are your pronouns?

□ they/them

□ 55 or older

| □ he/his □ she/hers □ other   |
|---|
| What is your race or ethnicity? (check all that apply)  |
| □ White □ Black/African American □ Hispanic/Latinx □ Asian □ Native American □ Pacific Islander □ [blank] |
| Do you identify as having chronic illness(es)   |
| □ Yes<br>□ No<br>□ Unsure   |
| Do you consider your chronic illness(es) to be invisible?   |
| □ Yes<br>□ No<br>□ Unsure   |
| Do you identify as having one or more disabilities?   |
| □ Yes<br>□ No<br>□ Unsure   |
| Do you consider your disability to be invisible?  |
| □ Yes<br>□ No<br>□ Unsure   |
| Survey stops if the responder has not answered "yes" to one of the questions about                        |

t their illness(es) or disability being invisible.

Thank you for your interest in illness and disability in academic librarianship. We are currently only seeking input from librarians with invisible or hidden illness and/or disabilities, but we appreciate your participation. We hope to eventually expand our research. For now, what made you interested in taking this survey?

Part II: Librarianship

How long have you been working as an LIS professional?

| <ul> <li>□ Less than 5 years</li> <li>□ 5–10 years</li> <li>□ 10–15 years</li> <li>□ 15–20 years</li> <li>□ 20+ years</li> </ul>   |
|--|
| How long have you been in your current position?   |
| <ul> <li>Less than 2 years</li> <li>2-5 years</li> <li>5-10 years</li> <li>10-15 years</li> <li>15-20 years</li> <li>20+ years</li> </ul>  |
| Whom have you disclosed your illness and/or disability to at work? [Check all that apply]  |
| <ul> <li>No one</li> <li>Colleagues I consider close friends</li> <li>Colleagues I work with regularly</li> <li>My direct supervisor (if not library director)</li> <li>Other library administrator/manager that I do not report to directly</li> <li>Library director</li> <li>Human Resources/disability office</li> <li>I am open about my illness/disability with everyone</li> <li>Other</li> </ul> |
| When did you choose to disclose to [fill in depending on the ones they check]  |
| <ul> <li>During the interview/hiring process</li> <li>Once I began working</li> <li>Upon receiving a diagnosis or beginning treatment</li> <li>When my illness/disability impacted my work</li> <li>As I built a personal relationship with colleagues</li> <li>When requesting accommodations</li> <li>Other</li> </ul>   |
| Have you requested accommodations for your illness and/or disability at your current institution?  |
| □ Yes □ No □ Unsure  |

If yes, the following three questions will appear:

If so, were your accommodations granted?

| in so, were your accommodations granted.   |
|--|
| □ Yes<br>□ No<br>□ Unsure  |
| What type of accommodation did you receive? Please check all that apply.   |
| <ul> <li>Work environment (furniture, office location, etc.)</li> <li>Job duties (shifting from in person to online instruction, front end to back end dutie etc.).</li> <li>Work schedule (change in hours, work from home, etc.)</li> <li>Other</li> </ul> |

Please tell us a little about that experience:

Part III: Working with invisible illness and/disability

Please respond to the following statements regarding your experience working with an invisible illness and/or disability. Rank the statements from strongly disagree to strongly agree.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly Agree N/A

#### **Hiring Process**

I have felt reluctant to apply for jobs that have requirements that might be difficult with my illness and/or disability (like lifting a certain weight).

I have decided not to apply for jobs because the requirements include things that would be difficult with my illness and/or disability (like lifting a certain weight).

My illness and/or disability required extra planning or accommodations for me to travel for in-person interviews.

The length of an in-person interview (roughly one business day) was difficult to manage because of my illness and/or disability.

I had to disclose my illness and/or disability during the interview process in order to make the interview accessible to me (requesting breaks during an in-person interview, etc.).

In order to prevent disclosure of my illness and/or disability, I hid my symptoms (pain, fatigue, etc.) during the interview process.

I have decided not to accept an in-person interview because of my illness and/or disability.

#### Daily Work Experience

I have decided not to disclose my illness and/or disability out of fear of not being believed.

I have decided not to disclose my illness and/or disability because it would be complicated and energy-consuming to explain.

I have disclosed my illness and/or disability to colleagues but have not been believed or have had my illness and/or disability minimized because of its invisible nature.

I have disclosed my illness and/or disability and faced professional repercussions from my colleagues and/or supervisor (being left out of projects, duties removed, etc.).

I have disclosed my illness and/or disability and faced social repercussions from my colleagues and/or supervisor (passive aggressive responses, confrontational behavior, etc.).

I have disclosed my illness and/or disability to my supervisor and received verbal support.

I have disclosed my illness and/or disability to my supervisor and received actionable support.

My illness and/or disability impacts my ability to complete regular work activities (reference desk shifts, sitting for long periods of time, providing instruction, attending events across campus, etc.).

My illness and/or disability impacts my decision to take on new projects or responsibilities in my current position.

#### **Professional Development**

My illness and/or disability impacts my ability to be active in the professional community (volunteering for committees, taking on leadership roles, etc.).

My illness and/or disability impacts my ability to be active in professional discourse (conducting research, publishing, presenting at conferences, etc.).

My illness and/or disability prevents me from travelling for professional events.

My illness and/or disability requires extra planning or accommodations to attend professional events.

My illness and/or disability has caused me to miss professional events such as conference sessions.

Virtual professional development opportunities are easier for me because of my illness and/or disability.

There is an understanding of invisible illness and/or disability within LIS professions.

There are active attempts to include individuals with invisible illness and/or disability within LIS professions.

LIS professional organizations provide adequate resources on inclusion of and support for individuals with invisible illness and/or disability.

LIS professional organizations are appropriate sources to provide support for LIS workers with invisible illness and/or disability.

I would benefit from a roundtable or other professional group dedicated to LIS professionals with disabilities.

#### **Accommodations**

My illness and/or disability impacts my daily work experience, but I did not know accommodations were an option to improve my situation.

I have requested and received accommodations for my illness and/or disability at my current place of work.

I have requested accommodations and felt the process was easy to navigate.

I have requested accommodations and felt the process was completed in a reasonable time frame.

I have requested but not received accommodations for my illness and/or disability at my current place of work.

I have decided not to request accommodations for my illness and/or disability out of fear of not being believed.

I have decided not to request accommodations for my illness and/or disability out of fear of repercussions from my colleagues (professionally or socially).

I have requested and/or received accommodations for my illness and/or disability and faced professional repercussions from my supervisor (being left out of projects, duties removed, etc.).

I have requested and/or received accommodations for my illness and/or disability and faced social repercussions from my supervisor (passive aggressive responses, confrontation behavior, etc.).

I have requested and/or received accommodations for my illness and/or disability and faced professional repercussions from my colleagues (being left out of projects, duties removed, etc.).

I have requested and/or received accommodations for my illness and/or disability and faced social repercussions from my colleagues (passive aggressive responses, confrontational behavior, etc.).

#### APPENDIX B. Dataset

The dataset from this study is available at the following DOI: <a href="https://doi.org/10.15786/17161328.v1">https://doi.org/10.15786/17161328.v1</a>). Openended responses have been removed to protect the anonymity of respondents.

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