

Hidden Barriers: The Experience of Academic Librarians and Archivists Living with Invisible Illness and Disability

By: Katelyn Quirin Manwiller, Samantha Peter, Amelia Anderson, and Heather Crozier

Recording Transcript

Speakers

Katelyn Quirin Manwiller and Samantha Peter

Katelyn Quirin Manwiller 00:00

Welcome to hidden barriers, the experience of academic librarians and archivists living with invisible illness and disability. This session will share recent research from Katelyn Quirin Manwiller, Samantha Peter, Amelia Anderson, and Heather Crozier presented by myself, Katelyn, and Samantha. We would like to thank our research partners who could not attend ACRL for their hard work on this project. We encourage you to use hashtag Hidden LIS with capitalization when tweeting about this session.

Katelyn Quirin Manwiller 00:32

Our research builds on a small, but growing field within LIS literature about the lives of library workers with disabilities. The majority of LIS research on disability focuses on addressing patron accessibility, often as a problem to be fixed without a larger context of disability studies. There have been only a few research studies on the experience of library workers with disabilities, all of which have been published in the last five years. The authors of this study came together as librarians living with and studying chronic illness and invisible disabilities in order to add a better understanding of the unique challenges facing LIS professionals with invisible or non apparent disabilities to the existing discourse.

Katelyn Quirin Manwiller 01:19

To do so we set out two objectives when submitting this research for and receiving Institutional Review Board approval. First, to identify barriers facing individuals with invisible illnesses and disabilities who are degreed LIS professionals working in academic libraries, libraries. Second, to determine ways academic libraries and LIS professionals can be more inclusive and accessible to those with invisible illness and disability.

Katelyn Quirin Manwiller 01:48

We also defined three research questions to guide our study. First, how does living with an invisible illness or disability impact the ability of full-time degreed LIS professionals in academic libraries to do their work? Second, how do degreed academic LIS professionals

handle disclosing their invisible illness or disability? And third, how do degreed academic LIS professionals face barriers or stigma in the workplace for their invisible illness or disability?

Katelyn Quirin Manwiller 02:19

To answer those questions. We created a survey targeted to individuals who hold a Master's in Library Science or equivalent and work at academic institutions as either librarians or archivists. We also required that participants identify as having an invisible illness and or disability. In consenting to do the survey, participants confirmed that they fit these parameters. We purposefully targeted a narrow subset of librarianship because there had not been a similar large scale quantitative study about librarians with disabilities published at the time we designed this survey and we weren't quite sure how well it would work out. We hope it will provide useful data that we can expand on in future broader surveys.

Katelyn Quirin Manwiller 03:05

As part of our survey, we provided definitions for chronic illness, disability, invisible, and accommodations, taken from disability literature and advocacy groups, to establish the context for our questions. You can find all four definitions in our handouts, but we included invisible here to help the audience understand the lived experience of our survey participants. Invisible in reference to illness and or disability is 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 movement senses or activities. It can also be referred to as non-visible, hidden, or non apparent.

Katelyn Quirin Manwiller 03:54

This survey was designed to be primarily quantitative questions to make it easier for participants to complete. Many people with chronic illness or disability have limited energy supplies and answering open-ended questions can be draining. The survey began with 14 multiple choice questions on demographics and experience with librarianship and disability in the workplace. There was one follow-up open-ended question. We asked participants a yes, no question, Have you received accommodations? And if they answered, yes, they were asked to please share what they could about that experience. The bulk of the survey was 38 Likert scale questions on that hiring process, daily work experience, including disclosure, professional development and accommodations. We also asked participants to leave their email address if they would like to be involved in follow-up interviews. Besides the initial participation consent and questions confirming self-identification, the participants were not required to answer any of the questions and could answer based on what best fit their experience.

Katelyn Quirin Manwiller 05:01

We created the survey in Qualtrics and shared it through ALA and Society of American Archivists listservs, as well as on social media. It was open for responses from April 15th

through May 15th, 2020. A total of 350 people consented to taking the survey. Most questions have between 270 and 290 respondents. Though a few were lower at around 170 to 200. And now I'll turn it over to Samantha with the survey results.

Samantha Peter 05:30

Hi, this is Samantha. For this section, we've chosen to highlight the questions or responses that had the biggest impact on us as researchers. For the purpose of this presentation, 15 minutes is obviously not enough time to fully dive into our data, so keep your eyes out for our published article for a comprehensive look. We are going to look at five overarching topics: disclosure, daily work experiences, accommodations, hiring, and professional development.

Samantha Peter 05:56

To begin, we are going to look at disclosure, specifically, the question of Who have you disclosed your illness and/or disability to at work? You can see the chart here of that data. As the chart shows, majority of respondents reported to colleagues they considered close friends, direct supervisors, and colleagues they work with closely. Only 41 respondents did not report their disability to their supervisor and 21 reported to other admin or other supervisor. The other section consisted of open-ended responses of direct reports to their department, informing nursing students, informing many on the list and some academic colleagues.

Samantha Peter 06:32

For this question of when did you disclose, participants were asked a series of questions based upon who they identified as having disclosed to in the previous question. They were asked in particular, when they decided to disclose to colleagues and supervisors. They were given a set of answers to choose from ranging from, as you can see in this graph, during the interview process, once I began working, when my illness/disability impacted my work and more with other as an option in every case. Because not all respondents responded to each of the following questions, the number of answers ranged. First participants were asked, when did you choose to disclose to colleagues you consider close friends? More than half 51% selected as I built a personal relationship with colleagues followed by when my illness impacted my work at 25%. Participants were then asked, when did you choose to disclose to colleagues you work with regularly? Most frequent answer selected was when my illness impacted my work at 37% followed by, as I built a personal relationship with colleagues. Next participants were asked questions of when did you choose to disclose to your direct supervisor? And when did you choose to disclose to other library administrator/manager or library director? The most frequent answer for all was when my illness impacted my work. Next participants were asked, when did you choose to disclose to the human resources/disability office? As expected, the most frequent answer was when requesting accommodations at 36%. Finally participants were asked if you

were open about your illness and or disability with everyone, when did you disclose? The most frequent answer was when my illness impacted my work at 27% followed closely by as I built a personal relationship with colleagues at 26%.

Samantha Peter 08:12

Next we're jumping into the daily work experiences category. The questions within this category consisted of a Likert scale of strongly agree to strongly disagree. First participants were asked to respond to the statement, I have decided not to disclose my illness and or disability out of fear of not being believed. 34% of respondents chose, agree or strongly agree while more than half 52% chose disagree or strongly disagree. Participants then responded to this statement, I have decided not to disclose my illness and or disability because it'd be too complicated and energy consuming to explain. In contrast to the previous question, more than half or 58% chose agree or strongly agree while 30% chose disagree or strongly disagree.

Samantha Peter 08:56

Next with daily work experiences, we looked at the repercussions of reporting. Participants responded to the statement, I have disclosed my illness and or disability and face professional repercussions from my colleagues and/or supervisor, being left out of projects, et cetera. Only 18% chose agree or strongly agree while more than half 54% chose disagree or strongly disagree. This again shows a positive sign that many participants, while stressing about the reporting process, did not face negative repercussions from reporting their illness and/or disability.

Samantha Peter 09:28

Next we're looking at the accommodation section. When the respondents were asked if they had requested accommodations, 32% said yes, and 61% responded with no, so not many of our respondents requested accommodations. Those who did were asked, what type of accommodations did you receive? Work environment was at 41%, Job duties sat at 12%, work schedule at 37% and other at 10%. Participants were then asked an open-ended question of, please tell us a little bit about that experience. The majority of respondents in the open-ended responses had good opinions of the accommodation process, which is overall positive. Many reported having a supportive work environment. Many people noted that they needed to create their own accommodations and multiple respondents noted having feelings of shame or insecurity during the process.

Samantha Peter 10:20

The hiring and interview section again, consistent of a Likert scale of strongly agree to strongly disagree. Some of the biggest takeaways in this, in this section we saw were 45% agreed or strongly agreed that they were reluctant to apply for jobs that have requirements that might be difficult for their illness and or disability, but 26% disagreed or strongly disagreed. However, respondents were asked if they would apply to jobs that would affect their disability. They were

fairly evenly split on deciding not to apply. 34% decided not to apply and 35% did. In order to prevent disclosure of their illness and or disability, respondents hid symptoms, pain, fatigue, et cetera, during the interview process, 47% agreed and strongly agreed. Overall, many respondents did not ask for accommodations during the interview process, but instead suffered. Many required extra planning for travel and struggled to manage the full day interview process.

Samantha Peter 11:19

Next we're jumping to the professional development section. Respondents were again, asked questions and given the Likert scale, strongly agree to strongly disagree. These Likert scale questions began with my illness and or disability impacts my ability to be active in the professional community. Participants were split in their responses with 36% strongly agreeing or agreeing and 32% strongly disagreeing or disagreeing. Participants' responses were also divided for the second statement, my illness and or disability impacts my ability to be active in professional discourse. 38% strongly agreed or agreed, and 46% strongly disagreed or disagreed.

Samantha Peter 12:01

Next respondents were asked whether there is an understanding of invisible illness and or disability within the LIS profession. Only 19% agreed or strongly agreed while 51% strongly disagreed or disagreed. Additionally, when asked whether they're active attempts to include individuals with invisible illness and our disability within the LIS profession, only 15% of respondents strongly agreed or agreed while 51% disagreed or strongly disagreed with this statement. This shows many respondents felt that there is not a representation or an understanding of invisible disability within the LIS profession. Next, Katie is going to take over to talk about the major takeaways.

Katelyn Quirin Manwiller 12:42

There are a few key results that stood out to us from this data. The first was that most disclosure occurred through personal relationships with colleagues. When participants did disclose to other colleagues, supervisors, or directors, it was largely because their illness or disability was impacting their work and when they were needed to request for accommodations. This suggests that disclosure is not something that happens unless librarians feel personally comfortable with colleagues or only because they must do so to meet their job duties. Despite this, participants reported generally positive and supportive responses from colleagues and supervisors when they did disclose with only a few reporting incidents of stigma or backlash. In addition, participants found the hiring process to be difficult, but most did not request accommodations to make it more accessible possibly because doing so would require disclosure. And lastly participants had mixed, experiences with the accessibility of professional development opportunities, but a majority found there to be an overall lack of support within librarianship for people with invisible illnesses or disabilities.

Katelyn Quirin Manwiller 13:51

Unfortunately COVID delayed our writing schedule a bit, but we hope to publish the full results of our study in the near future. After that we plan on conducting interviews with a select group of the survey participants to better understand their experiences. We are particularly interested in whether the type of illness or disability impacts a person's experience with the hiring process, disclosure, requesting accommodations, or participating in professional development. Eventually we hope to expand the survey beyond academic libraries and MLIS holders.

Katelyn Quirin Manwiller 14:25

Thank you for joining Hidden Barriers: The Experience of Academic Librarians and Archivists Living with Invisible Illness and Disability. We will now turn it over to a 10 minute live Q and A session. For additional questions, you can reach Samantha or myself at our email addresses or on Twitter. And lastly, you can find additional resources from this session at tinyurl.com/hiddenLIS.