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"Some Days, My Work Is Unbearable": The Impact of Chronic Illness and Disability on Recruitment and Retention for Workers in American Archival Repositories and Special Collections Libraries[1]

This survey-based article explores how chronic illness and disability impacts workers in archives and special collections, and focuses on how these individuals experience recruitment, retention, and working life in the United States. At the cultural level, it explores how the profession can create inclusive environments that enable all practitioners, including those with physical, mental, and neurological illness and/or disability, to enter, remain, and flourish in the field. The paper concludes with suggestions for systemic, structural change based on participant responses.

Introduction

Archival and special collections librarianship literature of the past two decades includes an increasing emphasis on diversity, equity, inclusion, and accessibility. Accessibility-focused literature, however, primarily focuses on user services in archives and special collections. A nascent body of literature investigates the intersection between accessibility, disability, and library workers. Through explorations of lived experiences of information professionals with chronic illnesses and/or disabilities,[2] this study considers how employers might make spaces, services, and policies more equitable and inclusive for workers. This study builds on these topics, focusing on US-based archives and special collections workers and exploring how they experience recruitment, retention, and working life. At the individual level, this study seeks to understand how chronic illness and other disabling conditions affect career paths and working lives in special collections and archives. At the cultural level, the study's

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1.   A version of this article was presented by the author, under the title, "The Impact of Chronic Illness and Disability on Careers in Special Collections Libraries and Archives," as part of the RBMS 2023 conference.

2.   This article predominantly employs person-first language to describe the experience of individuals with disabilities, due to my own preference and the importance of this practice in my own life. I acknowledge, however, the wide range of descriptions possible, and that not all people with disabilities or chronic illnesses use person-first language when describing themselves.

findings explore how the profession can promote systemic change that enables all practitioners—including those with disabilities or chronic illness[3]—to enter, remain, and flourish.

Personal and Professional Positionalities

Following Michelle Caswell, I value knowledge gained through lived experience.[4] I acknowledge how lived experience shapes my understanding of the relationship between disability, chronic illness, the archival and special collections labor market, and my research on this topic. For these reasons, I share this positionality statement: I identify as having a primarily physical, primarily invisible disability that I have had for over ten years. I have worked in the field for between ten and twenty years and am employed full-time at an academic institution where I perform chiefly administrative duties. Before I started this study in 2022, I never voluntarily disclosed my disability unless it demonstrably impacted my work. I never requested an accommodation, primarily because I witnessed negative repercussions in my immediate work environment when others did so. I changed jobs due, at least in part, to my disability rather than asking for an accommodation. This research project reflects my desire to explore accessibility in the field with more data than my lived experience offers and to effect change, making the profession more accessible for workers with chronic illness and/or disability.

This article's origins are not purely personal. Both the Society of American Archivists (SAA) and the Rare Books and Manuscripts Section (RBMS) of the Association of College and Research Libraries (ACRL) took important steps in promoting accessibility in the profession. The ACRL Code of Ethics for Special Collections Librarians, revised in 2020, states: "[Special Collections] practitioners work to recruit and retain a diverse and representative staff . . . regardless of . . . disability. . . . They actively strive to dismantle systems of oppression in institutional and professional spaces."[5] Similarly, in its Guidelines for Accessible Archives for People with Disabilities, endorsed in 2019, SAA addresses archivists' workplaces, noting that "accessibility is a vital element in promoting the archival profession's values of diversity, equity, and inclusion."[6] SAA also includes an active Accessibility and Disability Section, a membership group where "people with disabilities and their allies can learn from each other, share resources, and promote accessibility and disability representation

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3. See Appendix A.
4. Michelle Caswell, "Dusting for Fingerprints: Introducing Feminist Standpoint Appraisal," *Journal of Critical Library and Information Studies* 3, no. 2 (2021): 3, https://doi.org/10.24242/jclis.v3i2.113.
5. "ACRL Code of Ethics for Special Collections Librarians," Rare Books and Manuscripts Section, 2020, https://rbms.info/standards/code_of_ethics/
6. Society of American Archivists, "Guidelines for Accessible Archives for People with Disabilities," February 2019, 8–9, https://www2.archivists.org/sites/all/files/SAA%20Guidelines%20for%20Accessible%20Archives%20for%20People%20with%20Disabilities_2019_0.pdf

across the archival field."[7] Despite these guidelines and best practices, demographic information suggests that the field has room for improvement in terms of accessibility for workers with chronic illnesses or disabilities.

The World Health Organization (WHO) estimates that one in six people worldwide have a disability (16% of the global population, approximately 1.3 billion people).[8] The CDC estimates that one in four Americans (25%) have a disability[9] and that 60% of adults in the US have at least one chronic illness.[10] Professional association member surveys provide similar demographic information for archivists and special collections librarians with disabilities.[11] Although RBMS member surveys, conducted in 2015[12] and 2023,[13] did not include questions about disability or accessibility within the profession, a 2017 survey of American Library Association (ALA) membership found 2.91% reported having a disability.[14] A*Census II, a 2022 survey of "archivists and community memory workers" in the United States, found 16% reported having a disability.[15] These demographics suggest that librarians and archivists with disabilities[16] are either underrepresented, or chose not to self-report at rates higher than expected given available data from the CDC and the WHO.

My lived experiences, alongside the publication of RBMS and SAA documents calling for increased accessibility in the profession, inspired me to design a study exploring the following research questions: How does disability or chronic illness impact careers in special collections and archives, especially in recruitment, the hiring process, and retention? How can the archives and special collections profession promote systemic, structural support that enables all practitioners to enter and flourish in the field?

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   7.   Society of American Archivists Accessibility and Disability Section, "Welcome to the Accessibility & Disability Section!" https://www2.archivists.org/groups/accessibility-and-disability-section

   8.   World Health Organization, "Disability," 2023, https://www.who.int/news-room/fact-sheets/detail/disability-and-health

   9.   Centers for Disease Control and Prevention, "Disability Impacts All of Us," updated July 2024, https://www.cdc.gov/disability-and-health/articles-documents/disability-impacts-all-of-us-infographic.html

   10.   This includes, but is not limited to heart disease, cancer, diabetes, and asthma. Centers for Disease Control and Prevention, "About Chronic Diseases," October 4, 2024, https://www.cdc.gov/chronic-disease/about/index.html

   11.   "Disability" was the term used in the surveys.

   12.   Rare Books and Manuscript Section membership and Professional Development Committee, "2015 Membership Survey: Data Report," https://rbms.info/files/committees/membership_and_profes-sional/2015_RBMSDataReport.pdf

   13.   Rebecca Bramlett, email message to author, December 6, 2024. See Rebecca Bramlett et al., "Moving Forward: Membership and the Future of RBMS," *RBM: a Journal of Rare Books, Manuscripts, and Cultural Heritage*, 26, no. 1 (2025): 50–51.

   14.   Kathy Rosa and Kelsey Henke, "2017 ALA Demographic Study," ALA Office for Research and Statistics, 2017, http://hdl.handle.net/11213/19804.

   15.   Makala Skinner and Ioana G. Hulbert, "A*CENSUS II All Archivists Survey Report," Ithaka S+R, August 22, 2022, https://doi.org/10.18665/sr.317224.

   16.   Again, as "chronic illness" was not included in the survey, one can only speculate about individuals who so self-identify.

Literature Review

Scant literature explores the intersection of disability, chronic illness, and working as an archivist or special collections library practitioner.[17] The earliest considerations of disability and accommodations in the archival and special collections literature predate the Americans with Disabilities Act (ADA), but focus on access considerations for repositories as they serve *users* with disabilities.[18] This approach maintains a strong presence in scholarship, including explorations of archival repositories' website accessibility,[19] creating accessible outreach services,[20] assessment of physical and intellectual barriers to access for disabled communities,[21] and use of digital surrogates to promote accessibility of collections.[22]

Some literature explores the inclusion of disability in archival collections, in conversation with processing and access decisions. One strand of research explores the remediation of archival silences around disability, created via hegemonic collection development and descriptive practices.[23] Others disrupt traditional practices by documenting archival erasures of disability vis-à-vis feminist disability and user studies,[24]

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17.   I wrote this article in the fall of 2024, and it underwent peer review in January 2025. Therefore, this article does not reflect or engage with executive orders issued on or after January 20, 2025, related to accessibility.

18.   Lance J. Fischer, "The Deaf and Archival Research: Some Problems and Solutions," *American Archivist*, 42, no. 4 (1979): 464–468; Brenda Kepley, "Archives: Accessibility for the Disabled," *American Archivist* 46, no. 1 (1983): 42–51.

19.   Lora Davis, "Providing Virtual Services to All: A Mixed-Method Analysis of the Website Accessibility of Philadelphia Area Consortium of Special Collections Libraries (PACSCL) Member Repositories," *American Archivist*, 75, no. 1 (2012): 35–55, https://doi.org/10.17723/aarc.75.1.a716w067468262h5

20.   Kevin M. O'Sullivan and Gia Alexander, "Toward Inclusive Outreach: What Special Collections Can Learn from Disability Studies," *RBM: a Journal of Rare Books, Manuscripts, and Cultural Heritage*, 21, no. 1 (2020): 11–25, https://doi.org/10.5860/rbm.21.1.11

21.   Gracen Brilmyer, "'They Weren't Necessarily Designed with Lived Experiences of Disability in Mind:' The Affect of Archival In/Accessibility and 'Emotionally Expansive' Spatial Un/Belonging," *Archivaria*, 94, December (2022): 120–153, https://archivaria.ca/index.php/archivaria/article/view/13869

22.   Clare Withers et al., "Advancements in Primary Source Pedagogy: Catalysts for Collaboration, Context, and Change," *RBM: a Journal of Rare Books, Manuscripts, and Cultural Heritage*, 24, no. 2 (2023): 112–128. https://doi.org/10.5860/rbm.24.2.112

23.   Penny L. Richards, "Online Museums, Exhibits, and Archives of American History," *The Public Historian*, 27, no. 2 (2005): 91–100, https://doi.org/10.1525/tph.2005.27.2.91; Laurie Block, "'An Invented Archive:' The Disability History Museum," *RBM: a Journal of Rare Books, Manuscripts, and Cultural Heritage*, 8, no. 2 (2017): 141–154, https://doi.org/10.5860/rbm.8.2.288; Meghan Rinn, "Nineteenth-Century Depictions of Disabilities and Modern Metadata: A Consideration of Material in the P.T. Barnum Digital Collection," *Journal of Contemporary Archival Studies*, 5, Article 1 (2018): [unnumbered], https://elischolar.library.yale.edu/jcas/vol5/iss1/1; Anne Ricculli, "Curating History in the COVID19 Era: Philadelphia Epidemics and Nineteenth-Century American Women's Medical Education," *RBM: a Journal of Rare Books, Manuscripts, and Cultural Heritage*, 22, no. 1 (2021): 45–52, https://doi.org/10.5860/rbm.22.1.45

24.   Gracen Mikus Brilmyer, "'I'm Also Prepared to Not Find Me. It's Great When I Do, But It Doesn't Hurt If I Don't:' Crip Time and Anticipatory Erasure for Disabled Archival Users," *Archival Science*, 22 (2022): 167–188, https://doi.org/10.1007/s10502-021-09372-1

political/relational models for interrogating descriptive practices,[25] and negotiating new understandings of disability and archival practice through a critical disability studies framework during appraisal, arrangement, and description.[26]

Common throughout is the absence of lived experiences of workers. Research centering archivists and librarians with disabilities foregrounds legal requirements, such as Gilardi's summary of the ADA and considerations of its impact on archival repositories as employers.[27] A more recently published example provides a descriptive overview of invisible disabilities and the concurrent legal requirements for accommodation in the United States alongside strategies for allyship and recommendations for managers.[28]

Until the mid-2010s, library and information science (LIS) literature likewise focused on meeting information needs of users with disabilities, despite an early call to make the profession more inclusive through hiring practices and public-facing services.[29] In a content analysis of disability- and accessibility-related LIS literature published between 2000 and 2010, Hill finds emphases on surveying website accessibility, and describing and assessing services to persons with disabilities.[30] Early research on the effect of library recruitment and employment practices on workers with disabilities focuses on ways that systems intersect with disability in the workplace, and not, typically, on the ways in which individuals experience and live within those systems. These studies include legal descriptions,[31] recommendations for employers and managers as they navigate the accommodations process,[32] a consideration of disability

25. Gracen Brilmyer, "Archival Assemblages: Applying Disability Studies' Political/Relational Model to Archival Description," *Archival Science*, 18, no. 2 (2018): 95–118, https://doi.org/10.1007/s10502-018-9287-6

26. Sara White, "Crippling the Archives: Negotiating Notions of Disability in Appraisal and Ar-rangement and Description," *American Archivist*, 71, no. 1 (2012): 109–124, https://doi.org/10.17723/aarc.75.1.c53h4712017n4728

27. Ronald Gilardi, "The Archival Setting and People with Disabilities: A Legal Analysis," *American Archivist*, 56, no. 4, (1993): 704–713, http://www.jstor.org/stable/40293776

28. Ann Abney et al., "Understanding the Unseen: Invisible Disabilities in the Workplace," *American Archivist* 85, no. 1 (2022): 88–103, https://doi.org/10.17723/2327-9702-85.1.88.

29. Cara Barlow, "On My Mind: Don't Just Serve People with Disabilities—Hire Them," *American Libraries* 26, no. 8 (1995): 772.

30. Heather Hill, "Disability and Accessibility in the Library and Information Science Literature: A Content Analysis," *Library & Information Science Research* 35, no. 2 (2013): 137–42. https://doi.org/10.1016/j.lisr.2012.11.002

31. Jodi Johnstone, "Employment of Disabled Persons in the Academic Library Environment," *Austra-lian Library Journal* 54, no. 2 (2005): 156–163, https://doi.org/10.1080/00049670.2005.10721743

32. Anne-Marie O'Neill and Christine Urquhart, "Accommodating Employees with Disabilities: Perceptions of Irish Academic Library Managers," *New Review of Academic Librarianship* 17, no. 2 (2011): 234–258, https://doi.org/10.1080/13614533.2011.593852; Samantha Cook and Kristina Clement, "Navi-gating the Hidden Void: The Unique Challenges of Accommodating Library Employees with Invisible Dis-abilities," *Journal of Academic Librarianship* 45, no. 5 (2019), https://doi.org/10.1016/j.acalib.2019.02.010. Jessica Schomberg, "Disability at Work: Libraries, Built to Exclude." In *Politics and Theory of Critical Librarianship*, ed. Karen P. Nicholson and Maura Seale (Library Juice Press, 2018): 111–123.

justice and library values,[33] and theoretical explorations of systemic barriers found in cultures of resilience.[34]

Increasingly, LIS studies consider lived experiences of librarians with chronic illnesses and/or disabilities and explore solutions for systemic barriers through autoethnographies, or self-studies that interrogate lived experience(s) to generate understanding of cultural experiences.[35] Examples range widely and include: an author with a disability suggesting improvements to libraries as workplaces for employees with disabilities,[36] the impact of an invisible disability on growth and practice as a leader in academic libraries,[37] the importance of failure in information work,[38] requesting accommodations under the ADA and the impact of not being believed during that process,[39] the ethical challenges associated with "passing" as able-bodied,[40] and the cognitive costs of working in the LIS field—which seemingly glorifies vocational awe and resilience—as a person with a disability.[41]

Researchers also introduced a shift in survey- and interview-based research, foregrounding the impact on careers in libraries for individuals with chronic illnesses or disabilities. The earliest example, published in 2018, explored satisfaction rates of Canadian academic librarians with their jobs and workplace environments,[42] and subsequent survey-based studies center voices and experiences of librarians with disabilities. A qualitative survey articulates systemic workplace barriers, with findings that suggest impediments arise from lack of awareness and cultural stereotyping of library workers with disabilities.[43] Other survey-based studies center librarians with disabilities describing themselves

33.   Alana Kumbier and Julia Starkey, "Access is Not Problem Solving: Disability Justice and Libraries," *Library Trends* 63, no. 3 (2016): 468–491, https://dx.doi.org/10.1353/lib.2016.0004

34.   Christine M. Moeller, "Disability, Identity, and Professionalism: Precarity in Librarianship," *Library Trends* 67, no. 3 (2019): 455–470, https://dx.doi.org/10.1353/lib.2019.0006.

35.   Carolyn Ellis et al., "Autoethnography: An Overview," *Forum: Qualitative Social Research* 1, no. 12 (2011): https://www.qualitative-research.net/index.php/fqs/article/view/1589

36.   Schomberg, "Disability at Work."

37.   Jessica Olin, "My (Library) Life with Invisible Disabilities," *Letters to a Young Librarian* (blog), October 8, 2015, http://letterstoayounglibrarian.blogspot.com/2015/10/my-library-life-with-invisible.html

38.   Gina Schlesselman-Tarango, "Reproductive Failure and Information Work: An Autoethnography," *Library Trends* 67, no. 3 (2019): 436–454, https://dx.doi.org/10.1353/lib.2019.0005

39.   J. J. Pionke, "The Impact of Disbelief: On Being a Library Employee with a Disability," *Library Trends* 67, no. 3 (2019): 423–435, https://dx.doi.org/10.1353/lib.2019.0004

40.   Shanna Hollich, "What It Means for a Disabled Librarian to 'Pass': An Autoethnographic Exploration of Inclusion, Identity, and Information Work," *International Journal of Information, Diversity, & Inclusion* 4, no. 1 (2020): 94–107, https://doi.org/10.33137/ijidi.v4i1.32440

41.   Amelia M. Anderson, "Exploring the Workforce Experience of Autistic Librarians through Accessible and Participatory Approaches," *Library & Information Science Research* 43, no. 2 (2021): https://doi.org/10.1016/j.lisr.2021.101088

42.   Joanne Oud, "Academic Librarians with Disabilities: Job Perceptions and Factors Influencing Positive Workplace Experiences," *Partnership: The Canadian Journal of Library and Information Practice and Research* 13, no. 1 (2018), https://doi.org/10.21083/partnership.v13i1.4090

43.   Joanne Oud, "Systemic Workplace Barriers for Academic Librarians with Disabilities," *College & Research Libraries* 80, no. 2 (2019): 169–193, https://doi.org/10.5860/crl.80.2.169

and reflecting on their experiences working in libraries,[44] and academic librarians and archivists with "invisible illnesses and/or disabilities" describing their experiences.[45] This survey-based research provided an important framework for this article: it provides a community of practice in which to situate this survey of affected workers, and it provides inspiration for the methodological framework, explored below.

Methodology

In February of 2023,[46] I conducted a web-based survey of archivists and special collections librarians who self-identify as having a chronic illness or disability, using definitions drawn from the ADA and CDC.[47] Following practices modeled by Oud[48] and Quirin Manwiller, Anderson, Crozier, and Peter;[49] this survey used a methodology that allowed participants to remain completely anonymous and that required as little cognitive or physical energy as possible for respondents. The web-based survey primarily used Likert-scale questions coupled with three open-ended prompts, and the questions were inspired by those asked in the survey instruments centering the experiences of librarians with chronic illnesses and/or disabilities cited in this paper's literature review. I advertised the study on various professional listservs and discussion boards as well as social media,[50] and the survey tool was available for one month. Although designed to allow complete anonymity, the survey collected limited demographic information, including type of institution at which respondents worked, length of time in the field, employment status, and the type(s) and duration of chronic illness and/or disability. (See Appendix A.)

This article analyzes two types of data. Quantitative data produced from Likert-scale questions defines the ecosystem in which participants live and work. An open-ended coding strategy explores data from the open-ended questions and provides information on participants' lived experiences. The purpose is to use the data to answer the study's specific research questions, noted earlier.

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44. Robin Brown and Scott Sheidlower, "Claiming Our Space: A Quantitative and Qualitative Picture of Disabled Librarians," *Library Trends* 67, no. 3 (2019): 471–486, https://dx.doi.org/10.1353/lib.2019.0007

45. Katelyn Quirin Manwiller et al., "Hidden Barriers: The Experience of Academic Librarians and Archivists with Invisible Illnesses and/or Disabilities," *College & Research Libraries* 84, no. 5 (2023): 645–677, https://doi.org/10.5860/crl.84.5.645

46. This project was reviewed and determined exempt by the University of Arkansas IRB, protocol number 2011295958.

47. These definitions are imperfect and limiting, but using the legal terminology that governs American access to employment enables explorations of systemic barriers and suggests avenues for potential structural rather than individual change.

48. Oud, "Systemic Workplace Barriers."

49. Quirin Manwiller et al., "Hidden Barriers."

50. Listservs and discussion boards included the Society of Southwest Archivists, Ex-Libris-L, SAA, and the SAA Accessibility and Disability Section. Social media channels included personal Facebook and Twitter accounts. The Accessibility and Disability Section of SAA's Twitter channel cross-posted.

Results
About the Participants
Sixty-nine individuals participated, and sixty-three respondents met the study's inclusion criteria: the participant must self-identify as working in the archives and special collections field and as having a chronic illness and/or disability.[51] The majority were employed at an academic institution (62%), followed by museums (8%), independent research libraries and archives (5%), public libraries (5%), corporate libraries and archives (3%), government institutions (3%), religious orders (3%), and 10% selected "other" type of workplace.[52] Ninety-one percent reported working in the field for over five years; 43% worked in the field for ten years or more. Eighty-nine percent reported full-time employment and listed a wide range of work that they performed (Table 1).

TABLE 1

Responses to the question, "I perform the following type(s) of work in special collections libraries or archives: (select all that apply)."

Job Duties Performed	Number of Respondents[a]
Processing	48
Research services	39
Cataloging	36
Accessioning	35
Collection development	32
Outreach and programming	31
Donor engagement and management	28
Digital preservation	27
Preservation and/or conservation	27
Administration	26
Digitization	26
Exhibition development	26
Instruction	21

[a] Total number does not equal 63 as participants selected all options that applied.

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51.   As only questions establishing inclusion criteria were required, response rates to individual questions varies from sixty-three throughout this discussion.

52.   Includes consulting companies, membership libraries, educational but not academic institutions, and religious orders in academic institutions. Percentage reported does not equal one hundred due to rounding in this and all similar instances throughout the study.

Recruitment and Job Search

Participants noted if their chronic illness and/or disability affected their job searches and, if so, how. Sixty-seven percent (n = 40) participants indicated that their chronic illness and/or disability affected their job searches,[53] with a further 15% (n = 9) indicating that it might. Eighteen percent (n = 11) responded that chronic illness and/or disability had no impact. The ways in which participants experienced an effect on job searches included considerations of benefits packages, types of institutions, employment status of the position, work schedule, physical requirements, location, availability of medical specialists, and ability to work from home.

Participants also provided insight into if chronic illness and/or disability affected the specific types of work for which they applied. Responses to this quantitative question ranged widely: 39% (n = 24) replied that their chronic illness and/or disability affected the types of work for which they applied, 29% (n = 17) replied that it might, and 33% (n = 20) responded that it did not. Participants reflected further in response to an open-ended question on how chronic illness and/or disability impacts the types of work for which they applied. The inductive coding process used revealed three categories for analysis: physical, mental health, and structural considerations. Respondents most frequently mentioned assessing physical considerations when deciding if they would apply. Some mentioned avoiding positions that require long periods of standing, manual dexterity, or work such as pushing, pulling, or lifting. Respondents noted that buildings without elevators could deter them from applying, and many noted avoiding rigid scheduling, particularly around mealtimes, arrival and departure times, in-office work, and/or extensive travel.

Respondents mentioned mental health and structural considerations at roughly equal rates. Responses coded as "mental health considerations" included budgeting known causes of anxiety with job requirements and avoiding tenure-track, public service, and/or management positions due to associated stress levels. Responses coded as "structural considerations" related to benefits and the infrastructure required to manage long-term care needs. Specific examples include checking benefits availability and coverage before applying; applying for positions that provide adequate sick leave and flexible scheduling options; and seeking positions in geographic locations with the specialist medical care required to manage complex conditions. Finally, participants noted structural issues related to the job such as office environments, environmental conditions, and administrative practices that could exacerbate difficulties managing chronic illness and/or disability.

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53. Options presented throughout findings are quoted directly from survey instrument.

Accommodations and Disclosure

Accommodations, as defined and mandated by ADA Title 1,[54] exist to provide structural supports that allow individuals with disabilities to access and succeed in employment opportunities. Although most participants had lived with their chronic illness or disability for over five years, over half (54%, n = 33) reported that they had not requested workplace accommodations. By far the most reported reason (73%, n = 24) for avoiding accommodations requests was: "I don't want to ask unless I absolutely have to," followed by: "I don't know what to ask for" (42%, n = 14), and: "I am afraid of negative impacts on my job" (33%, n = 11). Only two participants indicated they requested an accommodation during the interview process.

Requesting formal accommodations is possible only with disclosure. However, survey participants indicated reluctance to disclose in the workplace. Thirty-three participants reported disclosing to their direct supervisor; twenty of the thirty-three who reported disclosing to their supervisor did so only "when illness and/or disability impacted work." After "direct supervisor," respondents indicated they were most likely to disclose to "colleagues [they] consider friends outside of work." Participants reluctantly disclosed to Human Resources (10, or ≅ 16% of all participants) and ADA coordinators (3, or ≅ 5%). One participant elaborated:

> if you report your mental illness to HR, etc., everything turns into a question of whether you are at risk of harming yourself or others. . . . So, I make sure no one knows about my lifelong struggle with a mental illness, but it's exhausting to cover it all the time.

Another participant wrote: "The ADA accommodation process was gaslighting and abusive and it needs to change." These responses provide insight into why disclosure and accommodations request rates are low.

Retention

Participants noted that they stayed in positions they otherwise wished to leave, to avoid triggers for their chronic illness and/or disability. Nevertheless, over half of respondents considered leaving their jobs (53%, or 33), and 32% changed jobs, in part, because of their chronic illness and/or disability. The top reasons cited for considering and/or changing jobs were "seeking a more accommodating work environment" (38%, or 24), followed by "unable to perform job duties," and "other" (14%, or 9 each). Under "other," participants noted reduction in benefits, toxic work environments, discrimination, and leaving before chronic illness and/

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54.   Office of Disability Employment Policy, "Accommodations," U.S. Department of Labor, https://www.dol.gov/agencies/odep/program-areas/employers/accommodations

or disability rendered their position impossible without accommodations. One participant reflected:

> in my current digital archives job, I don't have to lift things or walk much, and so I can mostly hide the symptoms of my condition from others. People have noticed sometimes, and offer sympathy/pity, which I think is kindly meant but I don't like it. It makes me feel like they see me as broken in some way, which is why I try to hide it instead.

Another participant noted that "with a chronic illness, I have many different care providers, and moving is not easy and wait times to see a new specialist are long. Long waits could negatively impact my health in the future." Illuminating the health care balancing acts required by survey participants illustrates reasons for both remaining in and leaving positions.

Although participants were hesitant to request accommodations, they provided insight into what accommodations would make their current position more accessible. Open, inductive coding of responses to the question "if you could change one thing about your job to make it more accommodating and accessible for you, what would you change?" revealed four thematic clusters: scheduling flexibility, physical changes, structural changes, and professional interpersonal relationships. Scheduling flexibility, including flexible work locations and hours, was cited by eighteen of the forty participants who responded to this question. Nine participants noted that physical changes would make their jobs more accessible, including turning off fluorescent lighting; access to a private office to use text-to-speech software; help with driving; storing cubic foot records boxes on lower shelves; and using more, smaller boxes for collections storage. Seven participants indicated structural changes, including permanent, benefited positions rather than contract work, improvements to the accommodation process, and affordable health insurance premiums. Three participants desired changes in interpersonal relationships, including clear communication norms around disclosure and more understanding bosses and colleagues.

Moving Forward: Suggestions for Making the Field Accessible

Participants shared a range of experiences in response to this survey. One participant noted: "having a physical disability has had almost no impact on [my] working in special collections and archives—it has impacted my career choice and living choices, but I feel fortunate to work in a profession that has shown only accommodation and understanding for my needs." Another wrote, "for my particular set of issues, I've found archives to be a very supportive and positive work environment." Other participants reported the opposite: bosses and colleagues who they felt did not take accommodation requests seriously, "gaslighting" accommodation processes, losing

jobs due to chronic illness, and not requesting accommodations for fear of negative repercussions. One participant noted that "some days, my work is unbearable … let's face it, the archives world and academic institutions are set up for able-bodied people." Another questioned their place in the field, noting: "I'm autistic and newly in a managerial position, and I am just always exhausted from trying to figure out the people around me. Maybe it's a sign I'm not suited for management in archives."

This dichotomy of experiences serves as a useful reminder that the analytical approach in this article centers commonalities in the data set and specifically considers system-wide implications, rather than individual. The commonalities do not to suggest that workers in archives and special collections who experience chronic illness and/or disability form a monolith. Rather, they highlight trends where systemic, structural change would benefit the field's practices; these, in turn, would benefit individuals, who experience chronic illness, disability, and employment differently.

A significant area for necessary systemic change suggested by responses to this survey is the accommodations process. No American workplace is required *only* to allow ADA requests; institutions can and should go above and beyond the legal baseline of the ADA to make archives and special collections more accessible workplaces. As shown by this survey, workers tend not to ask for accommodations unless absolutely necessary, due to fear of reprisal and/or prior negative experiences with the system. Additionally, the ADA process foregrounds bureaucracy and legal requirements and has a negative reputation. Institutions and individual supervisors in archives and special collections should know this and adjust their practices accordingly. Managers can make "flexibility" and "accommodation" watchwords of work culture, rather than the result of special requests. This survey particularly underscores the necessity of making more accessible interview processes a default, as only two of sixty-three participants requested an accommodation at the interview stage.

Participants also reported feelings of fearing disbelief. Supervisors can and should believe employees when they request accommodations to make their jobs more accessible. When they receive formal requests, supervisors can believe in the necessity of the request, and advocate for the employee with the ADA Office. Supervisors can support their employees making vulnerable requests in a bureaucratic process that all too often focuses on limiting liability for the institution rather than meeting an individual's needs.

Participants highlighted the care-related challenges associated with moving and changes jobs. Archival repositories and special collections libraries must stop relying on term-limited contracts and positions without benefits. Previous research indicates

how these positions are detrimental to everyone,[55] and this study demonstrates how they create barriers and risks for practitioners with chronic illness and/or disability. Contingent appointments do not provide the stability for benefits or access to care necessary for workers with chronic illness and/or disability, which actively contributes to the perpetuation of a system built on inequity.

Conclusion

This survey adds to research documenting the need for more accessible workplace practices through an exploration of lived experiences in special collections and archives. The recommendations suggested by such experiences are not easy. They require systemic changes that must often take place in institutions where the special collections library or archival repository is not the decision-maker for human-resources-related policy. This survey's participants illustrate how they have made accommodations for institutions for years—sometimes for entire careers. The profession can and should assume that burden. The alternative is to say the quiet part out loud: this profession is not accessible to people with chronic illnesses and/or disabilities, and creating a truly accessible, equitable, and inclusive field is a shared value in name only.

Acknowledgements

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55.   Micha Broadnax et al., "New England Archivists Contingent Employment Study Report to the Executive Board, January 2017," *New England Archivists*, 2018. https://www.newenglandarchivists.org/resources/Documents/Inclusion_Diversity/NEA%20Contingent%20Employment%20Study%20Final%20Report%202018-08.pdf; Stephanie Bredbenner et al., "'The Career Does Not Love You Back:' Impacts of Contingent Employment on Workers, Cultural Heritage Institutions, and the Archival Profession," *American Archivist* 87, no. 1 (2024): 131–154, https://doi.org/10.17723/2327-9702-87.1.131

Appendix A: Survey Instrument

The Impact of Chronic Illness and Disability on Careers in Special Collections Libraries and Archives

You are invited to participate in a research survey about the impact that having a chronic illness and/or disability has on your career as a special collections librarian and/or archivist. The study is conducted by Melanie Griffin, Director of Special Collections Services at the University of Arkansas in compliance with IRB standards. Please contact Melanie (melanieg@uark.edu) if you have any questions about the survey.

To participate, you must be 18 years or older, a current employee at a special collections library or archive, and self-identify as having a chronic illness and/or disability. If you decide to participate, understand that participation is voluntary and can be discontinued at any point without penalty. You can choose not to participate. There is no cost associated with participating in this study, and you will not receive compensation for participating. At the conclusion of the study, you have the right to request feedback about the results by contacting the researcher.

This study consists of an online survey. The survey will ask questions about your current employment status as well as questions related to your experiences working with chronic illness and/or disability while working in a special collections library or archives. It should take 10-15 minutes to complete the survey.

These questions may make you feel uncomfortable, and you may have a negative emotional reaction to them. If you find that the survey makes you uncomfortable, you are free to decide not to participate or to withdraw from the study at any time.

All information will be kept confidential to the extent allowed by applicable State and Federal law. Data will be anonymized before analysis, and results will only be presented in the aggregate. Records will be stored on secure university servers.

You may also contact the University of Arkansas Research Compliance office listed below if you have questions about your rights as a participant, or to discuss any concerns about or problems with the research:

Ro Windwalker, CIP
Institutional Review Board Coordinator
irb@uark.edu

By clicking "I consent" below you are indicating that you are 18 years old or older, have read this consent form, and agree to participate in this research study. You are free to skip any question that you choose or stop participating at any time without consequence. Please save a copy of this page for your records.

- ○ I consent, begin the study
- ○ I do not consent, I do not wish to participate

Q1: I work as a special collections librarian or archivist at a(n):
- ○ Academic institution
- ○ Corporate library / archives
- ○ Government institution
- ○ Independent research library / archives
- ○ Museum library / archives
- ○ Public library / archives
- ○ Religious order library / archives
- ○ Other, please list: _____

Q2: I perform the following type(s) of work in special collections libraries or archives: (select all that apply)
- □ Accessioning
- □ Administration
- □ Cataloging
- □ Collection development
- □ Digital preservation
- □ Digitization
- □ Donor engagement and management
- □ Exhibition development
- □ Instruction
- □ Outreach and programming
- □ Preservation and/or conservation
- □ Processing
- □ Research services
- □ Other, please list: _____

Q3: I have worked in special collections libraries and/or archives for:
- ○ 1 year or less
- ○ 2-5 years
- ○ 6-10 years
- ○ 10-20 years
- ○ Over 20 years

Q4: What is your current employment status?

- ○ Full-time
- ○ Part-time
- ○ Retired
- ○ Volunteer

Q5: How is your current position classified?
- ○ Professional staff
- ○ Support staff
- ○ Tenure track faculty member
- ○ Non-tenure track faculty member
- ○ Other, please list: _____

Q6: Do you self-identify as having either a chronic illness and/or a disability? This study defines "chronic illness" as an ongoing health condition, either physical or mental, that lasts a year or more and that requires ongoing medical attention and/or limits activities of daily living (adapted from https://www.cdc.gov/chronicdisease/about/index.htm). This study adopts the ADA definition of "disability": "a physical or mental impairment that substantially limits one or more major life activities" (https://www.ada.gov/topics/intro-to-ada/).

- ○ Yes
- ○ No

Skip to end of survey if No is selected

Q7: My chronic illness and/or disability is:
- ○ Primarily visible
- ○ Primarily invisible
- ○ Both

Q8: Which types of chronic illness and/or disability do you self-identify as having? (select all that apply)

- ☐ Chronic physical illness
- ☐ Chronic mental illness
- ☐ Mobility impairment
- ☐ Sensory impairment

Q9: I have had my chronic illness and/or disability:
- ○ Since birth
- ○ More than 10 years
- ○ 5-10 years
- ○ Less than 5 years

Q10: Do you supervise other employees?
○ Yes, I supervise full-time staff as well as part-time workers, student assistants, and/or volunteers when applicable
○ Yes, I supervise part-time, student assistants, and/or volunteers
○ Yes, I supervise volunteers
○ No

Q11: To whom have you disclosed your chronic illness and/or disability? (select all that apply)
☐ No one
☐ Colleagues I consider friends outside of work
☐ Colleagues I work with regularly
☐ Direct supervisor
☐ Library or archives director
☐ Human resources
☐ ADA coordinator
☐ I openly share about my chronic illness and/or disability with all colleagues
☐ Other, please describe: _____

Q12: When did you disclose your chronic illness and/or disability to colleagues you consider friends outside of work?
Display only if "Colleagues I consider friends outside of work" is selected in Q11
○ During the interview process
○ When negotiating a job offer
○ Upon receiving a diagnosis
○ Upon beginning treatment
○ When illness and/or disability impacted work
○ When requested accommodations
○ When colleagues became friends outside of work

Q13: When did you disclose your chronic illness and/or disability to colleagues you work with regularly?
Display only if "Colleagues I work with regularly" is selected in Q11
○ During the interview process
○ When negotiating a job offer
○ Upon receiving a diagnosis
○ Upon beginning treatment
○ When illness and/or disability impacted work
○ When requested accommodations
○ When colleagues became friends outside of work

Q14: When did you disclose your chronic illness and/or disability to your direct supervisor?
Display only if "Direct supervisor" is selected in Q11
○ During the interview process
○ When negotiating a job offer
○ Upon receiving a diagnosis
○ Upon beginning treatment
○ When illness and/or disability impacted work
○ When requested accommodations
○ When colleagues became friends outside of work

Q15: When did you disclose your chronic illness and/or disability to your library/archives director?
Display only if "Library/Archives director" is selected in Q11
○ During the interview process
○ When negotiating a job offer
○ Upon receiving a diagnosis
○ Upon beginning treatment
○ When illness and/or disability impacted work
○ When requested accommodations
○ When colleagues became friends outside of work

Q16: When did you disclose your chronic illness and/or disability to Human Resources?
Display only if "Human Resources" is selected in Q11
○ During the interview process
○ When negotiating a job offer
○ Upon receiving a diagnosis
○ Upon beginning treatment
○ When illness and/or disability impacted work
○ When requested accommodations
○ When colleagues became friends outside of work

Q17: When did you disclose your chronic illness and/or disability to the ADA coordinator?
Display only if "ADA coordinator" is selected in Q11
○ During the interview process
○ When negotiating a job offer
○ Upon receiving a diagnosis
○ Upon beginning treatment
○ When illness and/or disability impacted work

○   When requested accommodations
○   When colleagues became friends outside of work

Q18: When did you disclose your chronic illness and/or disability to all colleagues?
Display only if "All colleagues" is selected in Q11
○   During the interview process
○   When negotiating a job offer
○   Upon receiving a diagnosis
○   Upon beginning treatment
○   When illness and/or disability impacted work
○   When requested accommodations
○   When colleagues became friends outside of work

Q19: Have you ever considered changing jobs because of your chronic illness and/or disability?
○   Yes
○   No

Q20: What factors associated with your chronic illness and/or disability led you to consider changing jobs? (Select all that apply)
Display only if "Yes" is selected in Q19
☐   Seeking a change in employment status affecting benefits
☐   Seeking better health insurance
☐   Seeking a more accommodating work environment
☐   Unable to perform job duties
☐   Other, please describe: _____

Q21: Have you ever changed jobs, in whole or in part, because of your chronic illness and/or disability?
○   Yes
○   No

Q22: What factors associated with your chronic illness and/or disability led you to change jobs? (Select all that apply)
Display only if "Yes" is selected in Q21
☐   Seeking a change in employment status affecting benefits
☐   Seeking better health insurance
☐   Seeking a more accommodating work environment
☐   Unable to perform job duties
☐   Other, please describe: _____

Q23: Have you requested a workplace accommodation?

o   Yes
o   No

Q24: Why haven't you requested an accommodation? (select all that apply)
Display only if "No" is selected in Q23

☐   I don't need an accommodation
☐   Accommodations aren't available
☐   I don't know what to ask for
☐   I don't know how to request an accommodation
☐   I don't want to ask unless I absolutely have to
☐   The process is too stressful
☐   The process is too expensive
☐   I am afraid of negative impacts on my job
☐   I am afraid of my supervisor's response
☐   I am afraid of my colleagues' responses
☐   I am afraid that I will be treated differently after receiving an accommodation

Q25: Was your accommodation request granted?
Display only if "Yes" is selected in Q23

o   Yes
o   No
o   In part

Q26: What accommodation(s) did you request? (Select all that apply)
Display only if "Yes" is selected in Q23

☐   Adjustment to schedule
☐   Adjustment to work environment
☐   Adaptive or assistive technology
☐   Modification to job duties
☐   Other, please describe: _____

Q27: What accommodation(s) did you receive? (Select all that apply)
Display only if "Yes" is selected in Q23

☐   Adjustment to schedule
☐   Adjustment to work environment
☐   Adaptive or assistive technology
☐   Modification to job duties
☐   Other, please describe: _____

Q28: Did your request have any negative consequences?
Display only if "Yes" is selected in Q23

o   Yes
o   No
o   Maybe

Q29: Does your chronic illness and/or disability impact the types of special collections or archives work you apply to do?
o   Yes
o   No
o   Maybe

Q30: Please describe how your chronic illness and/or disability impacts the types of special collections or archives work you apply to do.
Display only if "No" is not selected in Q29

Q31: Does your chronic illness and/or disability influence your job search(es) more broadly?
o   Yes
o   No
o   Maybe

Q32: Does your chronic illness and/or disability influence your job search(es) by impacting (select all that apply):
Display only if "No" is not selected in Q31
☐   Type of institution(s) I apply to
☐   Location of institution(s) I apply to
☐   Benefits package offered by institution(s) I apply to
☐   Employment status of the position(s) I apply to
☐   Other, please describe: _____

Q33: When interviewing for a job, do you make a conscious effort to hide symptoms of your chronic illness and/or disability during the interview process?
o   Always
o   Most of the time
o   Some of the time
o   Rarely
o   Never

Q34: Do you make a conscious effort to hide symptoms of your chronic illness and/or disability while at work?
o   Always
o   Most of the time
o   Some of the time
o   Rarely
o   Never

Q35: Do you feel that your boss treats you differently than other employees in your unit because of your chronic illness and/or disability?

○ Always
○ Most of the time
○ Some of the time
○ Rarely
○ Never

Q36: Do you feel that your colleagues treat you differently than other employees in your unit because of your chronic illness and/or disability?

○ Always
○ Most of the time
○ Some of the time
○ Rarely
○ Never

Q37: Do you feel that your chronic illness and/or disability affects the professional development opportunities you are able to pursue?

○ Always
○ Most of the time
○ Some of the time
○ Rarely
○ Never

Q38: Do you feel that your chronic illness and/or disability affects the service opportunities you are able to pursue?

○ Always
○ Most of the time
○ Some of the time
○ Rarely
○ Never

Q39: How satisfied with the degree of flexibility you have with your work schedule in your current position?

○ Extremely dissatisfied
○ Somewhat dissatisfied
○ Neither satisfied nor dissatisfied
○ Somewhat satisfied
○ Extremely satisfied

Q40: Do you feel that your chronic illness and/or disability affects the opportunities you have to advance in your career?

- ○   Always
- ○   Most of the time
- ○   Some of the time
- ○   Rarely
- ○   Never

Q41: How frequently do you experience discrimination at work because of your chronic illness and/or disability?
- ○   On a daily basis
- ○   On a weekly basis
- ○   On a monthly basis
- ○   Infrequently
- ○   Never

Q42: How frequently do you experience harassment at work because of your chronic illness and/or disability?
- ○   On a daily basis
- ○   On a weekly basis
- ○   On a monthly basis
- ○   Infrequently
- ○   Never

Q43: How frequently do you experience microagressions at work because of your chronic illness and/or disability?
- ○   On a daily basis
- ○   On a weekly basis
- ○   On a monthly basis
- ○   Infrequently
- ○   Never

Q44: How satisfied with are you with your current job overall?
- ○   Extremely dissatisfied
- ○   Somewhat dissatisfied
- ○   Neither satisfied nor dissatisfied
- ○   Somewhat satisfied
- ○   Extremely satisfied

Q44: If you could change one thing about your job to make it more accommodating and accessible for you, what would you change?

Q45: Is there anything else you would like to share about your experiences working in special collections libraries and/or archives with a chronic illness and/or disability?