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CHAPTER 8

We Didn't Know:

How a Mid-career Research Project Taught Us about Disability, Advocacy, and Ourselves

Lee Ann Fullington and Jill Cirasella

Introduction

We—Lee Ann and Jill—are mid-career faculty librarians at different campuses of the City University of New York (CUNY), and we are both hard of hearing. Lee Ann has bilateral hearing loss and uses two hearing aids; Jill has single-sided hearing loss and uses only one. However, even with hearing aids, which do not restore normal hearing, our hearing loss complicates our lives at work and in the broader world. This chapter describes how we found community in each other, how our conversations about hearing loss led to a mid-career research collaboration, and how that collaboration launched us into a larger project of learning and advocacy.

Jill's Story

By some measures, I entered mid-career in 2013 when, shortly after being approved for tenure and promotion at Brooklyn College, I moved to a managerial position at The Graduate Center, CUNY's primary doctorate-granting institution. Lacking any training in management or leadership, I had applied with trepidation, interviewed

with trepidation, and accepted the position with trepidation. Despite my uncertainty, I took each of these steps because I believed that's what professional advancement required—that climbing the managerial ladder was a necessary component of career growth.

So, even though I had fantasized about spending the year after tenure reading novels and learning to draw, I found myself supervising three library units (Reference & Instruction, Circulation & Reserves, and Interlibrary Loan) and tasked with developing a fourth (Scholarly Communication). I had turned that first year of job security into a time of tremendous professional insecurity: could I do all I'd been hired to do, and could I do so with competence, clarity, and compassion?

The process of answering that question—the process of fumbling, improvising, learning, and improving—could be my mid-career tale. However, I believe my transition from early career to mid-career occurred not with the change from pre-tenure to post-tenure or the change from non-managerial to managerial but rather with the change from pre-tumor to post-tumor.

In 2015, I experienced drastic left-side hearing loss accompanied by the onset of persistent tinnitus, a constant and distracting ringing in my ear. Investigating these symptoms revealed a benign brain tumor known as an acoustic neuroma or vestibular schwannoma. I underwent surgery to remove the tumor in 2016, and the surgery and its complications were devastating. I healed, but my brain and body were forever changed. In addition to hearing loss and tinnitus, I had, and continue to have, balance problems, fatigue, and constant headaches.

I developed techniques for functioning in my new self, but I had to slow my pace and reevaluate my life and career goals. In particular, I could no longer envision ascending the administrative ladder. Indeed, I found myself struggling to stay on top of my existing job responsibilities. Supervising multiple units while also leading the library's scholarly communication initiatives had always been a juggling act, and post-tumor I simply could not keep all those balls in the air.

I approached the library director with a proposal to reduce the scope of my position, both for my sake and for the sake of the unit heads I supervised—they deserved more autonomy as well as a direct line to the library director. I am forever grateful that she had compassion for my situation, was open to my arguments, and agreed to assume oversight of the Reference & Instruction, Circulation & Reserves, and Interlibrary Loan units. I also recognize that my proposal might not have been successful if I hadn't held multiple forms of privilege: faculty status, tenure, a voice that was heard, the power to make major proposals, and a good relationship with the library director. And, it is important to note, if the shift had not been possible, I likely would have looked for a new job, one that would be more manageable for the new me.

The organizational changes allowed me to focus—more narrowly but more intently—on expanding the library's scholarly communication services. And, in time, I began to muse on forms of professional growth other than administrative advancement.

Lee Ann's Story

I have been working in academic libraries since 2006, beginning as a circulation supervisor. Finding that I enjoyed working with students and wanting to put my master of philosophy (MPhil) in popular music studies to use, I undertook the master of science in library and information science (MSLIS) with the intention of becoming a reference and instruction librarian in an academic library. I worked in support staff roles as I pursued the MSLIS and for a few years after graduation, and then in 2014 landed the position of health sciences librarian at Brooklyn College, where I recently earned tenure. On the tenure track, I was expected to publish peer-reviewed articles and conduct original research. To build these skills, I applied for and was selected to participate in the Institute for Research Design in Librarianship (IRDL), which provided training in social sciences research methods, such as the qualitative methods of interviewing individuals and moderating focus groups. I drew on these skills to conduct qualitative research projects for internal reports and programming and for publication when appropriate. For example, I successfully published a peer-reviewed article with a colleague regarding transfer students and their experiences.¹

Being a practitioner-researcher—working in a field and conducting research within the field, whether or not it is a requirement of the job—has been part of my professional identity dating back to my support staff roles. These previous experiences served me well on the tenure track, with its emphasis on research and scholarship. However, the road to tenure was intense, with high institutional expectations, and I worked at a pace that didn't allow for much work-life balance. I am a slow writer and was constantly pushing beyond my capacity, feeling like I was struggling to catch my breath. The demands of the tenure track, combined with my position's heavy instruction load, drained me. I felt like I was crawling to the finish line. This feeling of always running is, of course, symptomatic of the ableist culture of academia, which expects and rewards endless pushing at the expense of rest.

I must, however, acknowledge that the privilege of being hired into a tenure-track position and the further privilege of earning tenure afforded me the opportunity to conduct research as well as release time to work on these projects. I realize these entitlements I had as a junior faculty member are increasingly rare, as tenure-track lines are disappearing and many libraries rely heavily on part-time and contract labor.

After tenure, I looked at the years ahead and considered what would keep me going professionally, especially as I knew I did not want to go into library administration. I still had the desire to conduct research, and now I could set my timeline, pace, and priorities. Figuring out a research agenda that would sustain me in mid-career was the next step. Qualitative research tends to be done in teams, and I found appealing the prospect of partnering with and guiding colleagues who are new to social science research. There is so much joy in partnership and learning!

My hearing loss is just as central to our tale as my career trajectory. I have been hard of hearing my entire life, with hereditary hearing loss that runs in my father's family. I have been figuring out ways to cope with or cover up my hearing loss for many years, beginning in elementary school, when I would cheat on hearing tests by

raising my hand to pretend I'd heard a beep when I saw the nurse pressing the button on the audiometer, or hearing test machine. However, by the time I was studying for my MPhil degree in my late twenties, it became very clear to me that I needed to begin using hearing aids, just as my father had when he was the same age. I was working part time as a notetaker for students with disabilities at the university, and it became evident that my hearing loss had progressed to the point that I could no longer understand the lecturers—not well enough to comprehend the material, and certainly not well enough to take notes for other students—no matter where I sat in the classroom. I left my notetaker position before finishing my degree due to my frustration with my inability to hear and comprehend speech in this setting. Not long after graduation I got tested and fitted for my first pair of hearing aids. I started my first library job as a circulation supervisor a few months after getting my hearing aids, and I've relied on them throughout my library career.

Our Relationship: From Coincidences to Collaboration

Our relationship began in 2014 with a big coincidence: Lee Ann was hired by Brooklyn College to fill the line Jill had vacated in 2013. As predecessor and successor, we had many points of connection, even before the onset of Jill's hearing loss. We also had an easy, rewarding rapport. So, although we were both running full speed—pursuing opportunities, building skills, and hoping to prove ourselves—we made a point of meeting occasionally to catch up and compare notes.

One of the opportunities Lee Ann pursued soon after we met was participation in IRDL. Jill, aware that she was limited by her utter lack of social science research skills, envied Lee Ann's burgeoning expertise and enjoyed listening to her talk about research design and methods. Over time, her admiration evolved into a sense of possibility. Maybe she too could build these skills. Lee Ann, of course, championed the idea.

At the same time, Jill, who had already been through the tenure and promotion process, supported Lee Ann as she navigated the tenure track and built her CV. Further, since Lee Ann occupies the faculty line Jill vacated, Jill could help demystify Brooklyn College and its tenure and promotion expectations.

After Jill's diagnosis, discussions of research and tenure were supplanted by discussions of hearing loss and hearing aids, with Lee Ann able to provide support and guidance like few others could. Although the word "serendipity" has a positive connotation that may seem inappropriate for this situation, it was indeed serendipitous that Jill's hearing loss happened shortly after meeting Lee Ann. Further, our shared disability brought us closer together—a bittersweet silver lining.

Whenever we saw each other, we swapped observations and confided feelings about being librarians with hearing loss; clearly, there was a lot to unpack. But we were just two hard-of-hearing librarians, and there were certainly many more out there. What might they add to the conversation? How does hearing loss affect their professional lives? What do we all have in common, and how do our experiences diverge?

Suddenly we saw it: our conversations had led us to a research project. We could conduct a qualitative study of the professional experiences of hard-of-hearing librarians. Not only would this project allow us to engage with questions of deep personal interest, but it would also harness Lee Ann's passions for social science research and collaboration and provide Jill with an opportunity to learn the research skills she sought.

As we defined and refined our project, Lee Ann earned tenure, Jill adjusted her job, and we both completed some existing scholarly projects. Finally, we both had professional stability and some scholarly elbow room. The time was right to consider our priorities, pursue new research directions, and acquire new skills. With the security of tenure, we could look internally rather than externally for incentives; we could focus on what's meaningful and rewarding to us as librarians and individuals and prioritize projects that would support a greater good.

Our Research Project

Before we could begin our qualitative study of librarians with hearing loss, we needed to determine what had already been researched and written about library workers with disabilities. We scoured the library literature and quickly determined that far more has been written about library patrons with disabilities than library workers with disabilities. While this was not surprising, given that librarianship is a service-oriented profession, the contrast was stark. Thankfully, in recent years there have been several publications about library workers with disabilities.² Most mention hearing disabilities, but we found only one publication focused on hearing loss—an informative but brief article by a hard-of-hearing law librarian.³ Seemingly, our study would be the first of its kind in the library world. This *was* surprising—and exciting!

We decided that we would interview hard-of-hearing academic librarians about their lived professional experiences. Our hope was, and is, that our research would enable us to delineate common challenges for hard-of-hearing librarians and share strategies for coping with these challenges and advocating for oneself and others. We were developing our research design when the COVID-19 pandemic hit, delaying and then changing our research plans. We had intended to conduct in-person interviews in small, quiet spaces—both to optimize auditory conditions and to allow for speechreading (i.e., lipreading supplemented by observation of facial expressions and gestures). Therefore, we initially thought we would wait until we could again safely conduct in-person interviews without masking or distancing. Eventually, though, we accepted that pandemic risks and restrictions would continue for a long time, and we also became convinced that Zoom interviews could work well if we turned on auto-captioning (which is imperfect but helpful) and typed messages when necessary. Further, we wanted to ask interviewees, while their pandemic experiences were still fresh, about the hearing benefits and challenges of remote work, the difficulty of masked and/or distanced workplace communication, and the resulting need for informal or formal workplace accommodations. We are currently planning to recruit and interview research subjects during the 2021–22 academic year.

As we discussed our research plans, it emerged that we weren't closely connected to many people with hearing loss. We each have several hard-of-hearing family members and we had developed a close relationship with each other, but we were craving a larger support network. Our research, then, could serve the additional purpose of cultivating a community of academic librarians with hearing loss, building connections through shared experiences, challenges, and successes.

We further realized that we could begin building awareness about how hearing loss complicates librarians' work before conducting our research. We started by organizing a conference panel with two other hard-of-hearing librarians from CUNY.⁴ Several attendees expressed enthusiasm about participating in our study and encouraged us to repeat the panel at national library conferences. This feedback made us confident that our research has value and will help us build a community of advocacy and support.

Tenure, Productivity, and Vulnerability

Productivity looks different when viewed through a lens of disability. To uncouple our progress from academic capitalism and ableism and to view our research as joyful rather than obligatory was a privilege afforded us by having made it through the tenure process.⁵ We now have the luxury of doing research in a way that is manageable for both of us. We can acknowledge our own vulnerabilities and limitations and adjust our timeline as necessary—something we couldn't readily do when trying to fulfill tenure requirements. Further, we can turn our focus more outward: we can use our privileges of tenure and academic freedom to pursue research that will advance disability justice. We aim to learn, to share, and to advocate without being saddled with worries about the number of publications we'll generate or the prestige of the venues we'll present at.

As we planned and prepared our research project, and as we paused because of the pandemic, we had wide-ranging conversations about hearing loss, including the extra work listening demands of us and the ways in which we were thriving working from home, where we could better control our auditory environments and more easily retreat for rest. We read research that reinforced our experience that processing aural information takes longer, requires more focus, adds to cognitive load, and contributes to concentration fatigue and general exhaustion.⁶ We also immersed ourselves in the literature and discourse of disability, gaining a new vocabulary to understand and articulate our experiences. In doing so, we became much more attuned to our own physical and mental limitations.

Thanks to our sustained involvement in each other's careers, we have the mutual respect and trust that is essential for a research partnership, the trust to be vulnerable with each other, and the trust to respond compassionately. As we work together, we continually check in about how we are doing. Without ever doubting each other's diligence or commitment, we accommodate each other—sometimes ending a meeting early, sometimes volunteering to take on a task the other had been slated for, and sometimes adjusting larger goals. Composing this book chapter is a perfect case in point: we each experienced health and work setbacks in the weeks leading up to the chapter due date, and

we acknowledged that we needed to slow down to make time for rest and recuperation. This grace we gave each other was also shown to us by the book editors, who allowed us more time to complete our draft.

We Didn't Know

As we immersed ourselves in the preliminary stages of our research, it became clear that we still had a lot to learn about hearing loss beyond our own experiences. Indeed, we were even unclear about the language of hearing loss, which would be essential for determining and describing our potential participants. We already knew that “hard of hearing” is the preferred descriptor for people with hearing loss. “Hearing impaired” is no longer a recommended term, as it suggests being “less than” and is considered derogatory by many hard-of-hearing people.⁷ But what about “hearing impairment” as a noun? We knew that “hearing loss” was often used, but does it exclude people who were born hard of hearing and therefore didn’t “lose” their hearing? And are “hard of hearing” and “deaf” interchangeable, and, if not, what is the line between them? And should we use “Deaf” with a capital “D” or “deaf” with a lowercase “d”? We didn’t know!

We even had to admit that we had questions about our own identities. For example, Lee Ann has moderate to severe hearing loss in both ears and struggles to understand speech without her hearing aids. Can she describe herself as deaf? We didn’t know! Jill’s hearing loss is only on her left side, but she contends daily with balance problems, headaches, and fatigue caused by her acoustic neuroma and its removal. Does she qualify as disabled? We didn’t know! Some of our many questions could be answered with a quick search. But some—e.g., the distinction between “Deaf” and “deaf”—are not so simple and involve considerable debate.⁸ On these topics, we are continually learning from the Deaf, deaf, hard-of-hearing, and disabled folks we follow on Twitter. Their posts and conversations build our understanding, deepen our interest in disability justice, and help us feel connected to a larger community.

With all that we didn’t know, we felt the need to limit our study to participants whose situations we were equipped to discuss and understand. We did not want to unwittingly alienate, upset, or offend interviewees because of our areas of ignorance. Therefore, we decided that for our initial project, while we are still learning, we would focus on librarians who, like us, use hearing aids. We decided to use hearing aids as a proxy, albeit an imperfect one, for hearing loss that is significant enough to cause communication problems but not so profound that hearing aids are ineffective.

We hope to conduct additional, more inclusive studies as we learn more and meet potential collaborators who would bring additional perspectives to our research. For example, we look forward to collaborating with someone who knows sign language in order to be able to interview librarians who rely on sign language. Also, we are both considering pursuing disability studies certificates, both to inform our research and to deepen our understanding of disability justice issues. Whether or not we ultimately pursue certificates, we want to use our privilege as tenured librarians to advance disability justice in the profession.

Conclusion

We began our collaboration with an idea for a single qualitative study of librarians with hearing loss—an idea that turned out to be a springboard into a whole mid-career research and advocacy agenda. We are eager to carry out our study soon, while at the same time relieved that our tenured status allows us to proceed at a pace that works for us and take the time to better educate ourselves about disability. We were sapped by the tenure track and health crises, but we are again finding joy in our work—in our collaboration, in learning, and in the prospect of building a community.

We seek to contribute to both the scholarly and non-scholarly conversations about library workers with disabilities. Freed from the constraints of the tenure track, we can look beyond research-based publications and formal conference presentations to more practical contributions and informal modes of sharing. As Yerbury and Yerbury write, “Disabled academics can offer straightforward solutions to ableism, including changes to spaces; the use of assistive technologies for more inclusive teaching and learning designs; and modifying policies related to administrative workflows, recruitment, and promotion.”⁹ We plan to leverage our privileges of tenure and academic freedom to work towards a more equitable, inclusive, and accessible library profession.

Notes

1. Matthew Harrick and Lee Ann Fullington, “Don’t Make Me Feel Dumb’: Transfer Students, the Library, and Acclimating to a New Campus,” *Evidence Based Library and Information Practice* 14, no. 3 (2019): 77–91, <https://doi.org/10.18438/eblip29512>.
2. Jessica Schomberg, “Disability at Work: Libraries, Built to Exclude,” in *The Politics of Theory and the Practice of Critical Librarianship*, eds. Karen P. Nicholson and Maura Seale (Sacramento, CA: Library Juice Press, 2018), 111–23, https://cornerstone.lib.mnsu.edu/lib_services_fac_pubs/149; Jessica Schomberg and Shanna Hollich, eds., “Disabled Adults in Libraries,” Special issue, *Library Trends* 67, no. 3 (Winter 2019), <https://muse.jhu.edu/issue/40307>; Joanne Oud, “Systemic Workplace Barriers for Academic Librarians with Disabilities,” *College & Research Libraries* 80, no. 2 (March 2019): 169–94, <https://doi.org/10.5860/crl.80.2>; Robin Brown and Scott Sheidlower, *Seeking to Understand: A Journey into Disability Studies and Libraries* (Sacramento, CA: Library Juice Press, 2021).
3. Mari Cheney, “The Hearing-Impaired Law Librarian: Navigating Silent Spaces,” *AALL Spectrum* 25, no. 3 (January/February 2021): 34–37.
4. Jill Cirasella, Lee Ann Fullington, Monica Berger, and William Gargan, “Shhh-tereotypes: A Conversation among Librarians with Hearing Loss,” *Urban Library Journal* 27, no. 2 (2021), <https://academicworks.cuny.edu/ulj/vol27/iss2/3/>.
5. Nicole Brown and Jennifer Leigh, eds., *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education* (London: UCL Press, 2020).
6. Dorothea Wendt, Birger Kollmeier, and Thomas Brand, “How Hearing Impairment Affects Sentence Comprehension: Using Eye Fixations to Investigate the Duration of Speech Processing,” *Trends in Hearing* 19 (2015): 1–18, <https://doi.org/10.1177/2331216515584149>; Jonathan E. Peelle, “Listening Effort: How the Cognitive Consequences of Acoustic Challenge Are Reflected in Brain and Behavior,” *Ear and Hearing* 39, no. 2 (March/April 2018): 204–14, <https://doi.org/10.1097/AUD.0000000000000494>; Benjamin W. Y. Hornsby, Graham Naylor, and Fred H. Bess, “A Taxonomy of Fatigue Concepts and Their Relation to Hearing Loss,” *Ear and Hearing* 37, no. S1 (July/August 2016): 136S–144S, <https://doi.org/10.1097/AUD.0000000000000289>; Janneke Nachttegaal, Joost M. Festen, and Sophia E. Kramer, “Hearing Ability in Working Life and Its Relationship with Sick Leave and Self-Reported Work Productivity,” *Ear and Hearing* 33, no. 1 (January 2012): 94–103, <https://doi.org/10.1097/AUD.0b013e318228033e>.

7. "Community and Culture – Frequently Asked Questions," National Association of the Deaf, accessed November 8, 2021, <https://www.nad.org/resources/american-sign-language/community-and-culture-frequently-asked-questions/>.
8. We did learn that in academic writing "Deaf" with a capital "D" tends to denote the sociolinguistic community of sign language users, whereas "deaf" with a lowercase "d" refers to the physiological attribute of having hearing loss; see Teresa Blankmeyer Burke and Brenda Nicodemus, "Coming out of the Hard of Hearing Closet: Reflections on a Shared Journey in Academia," *Disability Studies Quarterly* 33, no. 2 (2013), <https://doi.org/10.18061/dsq.v33i2.3706>.
9. Justin J. Yerbury and Rachel M. Yerbury, "Disabled in Academia: To Be or Not to Be, That Is the Question," *Trends in Neurosciences* 44, no. 7 (July 2021): 507–9, <https://doi.org/10.1016/j.tins.2021.04.004>.

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