

The Burden of Survival: How Doctoral Students in Computing Bridge the Chasm of Inaccessibility

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ABSTRACT

Despite efforts to support students with disabilities in higher education, few continue to pursue doctoral degrees in computing. We conducted an interview study with 12 blind and low vision, and 7 deaf and hard of hearing current and former doctoral students in computing to understand how graduate students adjust to inaccessibility and ineffective accommodations. We asked participants how they worked around inaccessibility, managed ineffective accommodations, and advocated for tools and services. Employing a lens of ableism in our analysis, we found that participants' extra effort to address accessibility gaps gave rise to a *burden of survival*, which they sustained to meet expectations of graduate-level productivity. We recommend equitable solutions that acknowledge taken-for-granted workarounds and that actively address inaccessibility in the graduate school context.

CCS CONCEPTS

• **Human-centered computing** → **Accessibility**; • **Social and professional topics** → **Computing education**.

KEYWORDS

Accessibility, Higher Education, Computing Education Research, Ableism

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1 INTRODUCTION

In the United States, the National Science Foundation's Survey of Earned Doctorates (SED)¹ in 2017 reported as few as 2.9% of doctoral graduates in computing indicated a functional limitation². Of those,

¹<https://www.nsf.gov/statistics/srvydoctorates/>

²Early versions of the SED asked graduates to indicate their disability identity while later versions asked about functional limitations. This change in wording may result in an overestimation of the number of doctoral students in computing who identify as having a disability [6, 28].

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66 or 3.6% of respondents indicated a vision impairment, and 15 or 0.8% indicated a hearing impairment [28]. By comparison, in 2016, 5.54% of computing undergraduate students reported having a disability [28], indicating a shrinking pipeline of students who pursue advanced degrees.

In domains across the technology industry, increased representation of researchers with disabilities can improve innovations that harness and augment human behavior and ability, for example, improving artificial intelligence for pedestrian recognition of self-driving cars [7, 10, 33]. Thus, underrepresentation at the highest levels of institutional research and innovation underscores the need to better support students with disabilities. Inaccessibility at the graduate level creates barriers to success for students with disabilities [21, 35], impeding the number of graduates who then enter the technology industry. We investigated how PhD students in computing and related fields bridge the chasm of inaccessibility at the doctoral level. We interviewed 12 blind and low vision and 7 deaf and hard of hearing (DHH) current and former computing doctoral students about the time and energy they dedicated to managing trivial and non-trivial access-related tasks, addressing ineffective accommodations, and self-advocating for solutions in service of improving inaccessibility. The findings presented in this paper highlight and investigate the circumstances that created additional responsibility for participants; this work represents a portion of findings from a larger project. Specifically, we found that participants employed a constellation of strategies to address inaccessibility and insufficient accommodations, adding to substantial overhead in terms of additional tasks they took on to manage such responsibilities. We identified myriad formal and informal forms of auxiliary effort that participants used to address inaccessibility, and we show how this additional labor constituted a *hidden burden* on top of expected graduate school responsibilities. Contributions of this work include empirical findings (1) contextualizing the kinds of additional labor that blind, low vision, deaf and hard of hearing PhD student participants encountered, (2) showing how participants traversed inaccessibility they experienced, including issues faced after they should have received accommodations. We present findings that emerged via an analytic lens of ableism, demonstrating how the additional labor they expended gave rise to a *burden of survival* that participants took on despite mechanisms in place ostensibly designed to help.

A note on terms: We cautiously describe our findings as a *hidden burden* that participants took on to manage accommodations necessary for their academic endeavors. We contrast and differentiate this notion of a hidden burden apart from ableist notions of "challenges" that people with disabilities encounter [24, 34]. Unlike (often incorrect and misguided) assumptions about disability "challenges,"

our findings suggest that participants commanded a hidden set of *unaccounted-for* tasks and responsibilities that emerged with or without accommodations (however in/effective) that were allocated via official channels. For example, a student may request access to a print document for a course and be assigned a human reader who has limited availability. While communicating scheduling needs with the human reader (which takes additional unaccounted-for time and energy), the student may also investigate other avenues to gain access to the print material, including seeking peer help (using social capital), or trying third party applications or services (incurring out-of-pocket costs). Our findings indicated students expended time-consuming effort in addition to accommodations, or in lieu of pursuing (often complicated and protracted) formal solutions. We call this unaccounted-for and extraneous time and energy, the *hidden burden of survival*.

2 RELATED WORK

Most research about disability and accessibility in post-secondary institutions focuses on undergraduate student experiences or accommodations and assistive technologies used to address coursework. Our work examines the experiences of blind, low vision, deaf and hard of hearing (DHH) doctoral computing students through a lens of ableism. We draw on Disability Studies literature to inform our understanding of ableist notions, its material impact on disabled³ people, and its role in higher-education institutions.

2.1 Accommodations and Workarounds in Higher Education

Institutions of higher-education are required by law [11] to provide reasonable accommodation to secure equal access to materials and services for students to successfully complete their degree. University disability services offices are typically singularly tasked with addressing this accommodation requirement [26]. However, the process of obtaining and using accommodation may not be seamless, depending on how knowledgeable students and disability services offices are about student needs [22, 25], what resources are available [25], and on students' involvement in requesting accommodations [5, 20, 25]. Students enrolled in post-secondary institutions are responsible for attaining necessary accommodations [22], a level of personal obligation that differs from institutional support at the secondary level [26]. However, disclosure and pursuing issues of accommodation and non-compliance can be fraught with considerations for stigma associated with disability and for balancing disclosure/accommodation issues over academic success, complicating if and how students pursue services [5]. Thus, many programs and organizations focused on student success help connect students to resources and practices necessary to obtain the accommodations they need [9]. We seek to understand the in/effectiveness of accommodations for graduate students focused on research, how they use workarounds, what recourse they exercise to circumvent ineffective accommodations, and the impact of these strategies on student productivity and success. For people with disabilities, encountering inaccessibility is a regular affair and as such, devising creative workarounds becomes a common task. So much

about the designed, built environment presumes that inhabitants or users are not disabled such that workarounds are often the default reflexive reaction of individuals with disabilities [13]. Students with disabilities in higher-education often seek a range of technologies, services and other forms of help to address inaccessibility. For example, blind and low vision students may seek Braille displays and human readers to gain access to print and graphical materials. Deaf and hard of hearing students may desire American Sign Language (ASL) interpreters or captioning of meetings, presentation, or class lectures [21, 35]. Other increasingly common approaches include outsourcing menial tasks to free lance workers, or accessibility "gig" workers, such as BeMyEyes [14] or Aira [1].

2.2 Ableism

We consider notions of ableism as discussed in Disability Studies literature, most notably, attitudes that treat nondisabled ability as superior over those with disabilities [13, 24]. Ableist attitudes are found in cultural norms (e.g., when we presume sight, hearing are given characteristics) and in social and institutional infrastructure (e.g., when we assume accommodations are an exception that require explicit requests) [13, 24]. Traces of ableist tradition are esconced in bias in academic institutions [13]. Ideals such as autonomous effort and meritocratic award structures, in particular, inherently assume a certain type of body identity over others [13]. Ableism in academia has material impacts on the participation of disabled academics partly due to the norms embedded in academic life [8, 13]. For students, ableism permeates assumptions within the university context that disability is an individual "problem" that requires management and "accommodating" [20].

As a conceptual device, ableism helps us to "understand the social and cultural production of ability and ableness and the ability-preferences," [20] and enables us to position programs, services, and even attitudes of whole groups of people (i.e., members of the university faculty or disability services) as mechanisms executing upon a foundation of certain assumptions about dis/ability [13]. Ableism may also be used as an analytic lens by centering students' experiences as a consequence of assumptions and expectations built into the university institution (and not necessarily as a consequence of any impairment of theirs) [13, 20]. Our goal in adopting an ableist lens is to involve a critical examination of the impact of existing structures on students' experiences with inaccessibility.

2.3 Graduate Experience for Students with Disabilities

Most prior research focused on post-secondary disabled student success is centered on the undergraduate experience [3, 4, 9, 17, 23], including access to coursework and assistive technologies [15, 16]. Graduate student experiences differ significantly [21, 25, 32, 37], particularly those in doctoral programs, where research takes priority. Research focused on disabled graduate students investigated primarily master's students, finding that students are disadvantaged when they do not have access to technical resources, and that they require self-advocacy skills to address passive and active resistance to accommodation requests [12, 25, 38]. Although such research provides perspective on aspects of masters level graduate education, it may miss unique characteristics to the doctoral experience. Such

³We refer to Disability Studies literature recognizing identity-first and person-first language used depending on individual personal preferences[24].

characteristics may include emphasis on research productivity over course grades, financial instability due to reliance on stipends, managing professional and personal relationships with future careers in mind, among others [21, 35]. We examine the consequences of dealing with inaccessibility and ineffective accommodations, specifically for doctoral computing students. The broad nature of our inquiry allowed us to follow-up with students about external forces that may have impacted their experience.

3 METHOD

The findings presented in this paper highlight and investigate the circumstances that created additional responsibility for participants; this work represents a portion of findings from a larger project. We present the method employed for the larger project and then discuss specific analytic turns for this paper.

We conducted a semi-structured interview study with 19 blind, low vision, deaf and hard of hearing (DHH) doctoral students in computing and related fields. We intentionally recruited participants who identified as blind, low vision, or DHH to understand how students incorporated assistive technologies as well as accessible mainstream devices in their research and coursework. Interviews were conducted in person, over the phone, via (ASL interpreted) video relay service, on chat, or video-conference call, depending on the preferences of the participant. Each interview lasted between 30 minutes and 90 minutes. We recruited participants who were currently, or recently, enrolled in a PhD program in computing or a related field. Participants included those who were currently enrolled (at the time of the interview), and those who had graduated or otherwise left their program within a 10 year timeframe. We anticipated the population of participants who fit our recruitment criteria to be small, and also sought those who might have experiences relevant to current technologies (*i.e.*, screen readers or automatic speech recognition technologies), thus the 10 year timeframe for those in computing fields. We asked participants about their experiences in graduate school broadly, and also about dealing with inaccessibility, accommodations and other aspects of meeting graduate expectations.

For findings presented in this paper, we focused on responses describing how issues of inaccessibility were addressed and by whom (what issues were resolved, when did participants seek help from peers or institutional offices, such as disability services, who or what else effectively addressed accessibility issues, if any). We also examined responses that described strategies participants used to independently resolve accessibility issues, including personal and professional considerations that informed their efforts.

3.1 Participants

Participants were in their first through seventh year in a PhD program (Table 1). For those who graduated or left, the years in the table indicates the number of years in the program. Of the 19 participants, 15% identified as women (the Taulbee Survey reported women comprised 21% of PhDs awarded in computing and related fields in 2018 [2]). Five participants identified as international students, 14 were enrolled at the time of interview, five had graduated or left their program at the time of their interview. Due to small numbers and for reasons of anonymity, we refrain from identifying who left their programs without graduating.

As the population of individuals who identify as graduate students with disabilities in computing or related fields is very small, we intentionally omit identifying specific programs or research topics, gender identities, and citizenship or matriculation status. We use gender neutral language to avoid identifying the small number of women participants. All but one DHH participant identified as d/Deaf⁴, therefore, we opted to identify all participants as DHH to maintain anonymity.

Participants reported using a wide range of technologies and services. We refrain from identifying which participants used specific resources, instead we list technologies in the aggregate: Blind and low vision participants reported using tools such as, but not limited to: screen readers, Braille displays, Aira, BeMyEyes, audio textbooks, tactile graphics; other commonly used tools and languages included MatLab, Adobe Acrobat, Perl, Bash, Eclipse, JGrasp, JavaScript, Assembly, quantum mechanic and data visualization software. DHH participants reported using ASL interpreters, video-relay services, captioning and CART (Communication Access Realtime Translation) services; other tools included Slack, email, Google Docs, in lieu of in-person meetings.

3.2 Data and Analysis

All interviews were audio recorded and transcribed prior to analysis. We used a qualitative approach in our analysis, grounded in the experiences of the participants, maintaining an open and flexible approach, with continued analysis guiding subsequent interviews [18, 36]. We employed inductive coding in our initial passes, with three researchers independently coding the first five interviews, followed by discussion and clarification of codes [31]. Subsequently, reflexive weekly discussion followed interview and coding sessions so that emerging categories were continually assessed and clarified alongside new data. As our initial interview questions were focused on graduate life in general, with follow ups about how participants navigated inaccessibility and institutional process, an analysis grounded in participant experiences allowed relevant themes to emerge across different experiences. For example, we coded instances of self-advocacy across different contexts, such as with course instructors, faculty advisors, disability services staff, etc., enabling tensions between social relationships and workaround needs to emerge.

Our analysis leading to the findings presented in this paper focused on how students worked around inaccessibility, including how they handled consequences of inadequate accommodations. We identified issues that arose despite accommodations, and analyzed how these imperfect solutions impacted graduate life for participants (Table 2). We examined impact on their time, how much effort they expended, and social and emotional considerations. In applying an ableist lens in our analysis, we acknowledged that accommodations could be inadequate and that institutional or structural procedures may have embedded expectations about what constituted accessibility resolution; we used this lens to analyze the material impact on participants.

⁴Capitalizing Deaf indicates those who identify as members of the Deaf Community [30].

Table 1: Participant Information. Note that B11's years in program were inferred from discussion in interview.

Participant	Vision / Hearing Status	Years in Program	Area of Research
B1	blind	2	Computing
B2	low vision	5	Computing
B3	low vision	4	Computing
B4	low vision	3	Computational Sciences
B5	blind	4	Computing
B6	blind	6	Computing
B7	blind	4	Computing
B8	low vision	3	Computational Sciences
B9	blind	5	Computational Sciences
B10	blind	6	Computing
B11	blind	2	Computational Sciences
B12	blind	2	Computing
D1	DHH	4	Computing
D2	DHH	5	Computing
D3	DHH	1	Computing
D4	DHH	2	Computing
D5	DHH	5	Computing
D6	DHH	7	Computing
D7	DHH	1	Computational Sciences

4 FINDINGS

Our findings showed that participants took on additional labor to address inaccessibility and inadequate accommodations in pursuit of academic success. Participants employed a number of small and large, and formal and informal tasks and strategies to bridge inaccessibility gaps. Further, the extra effort they engaged and prolonged time they withstood to deal with mundane and nontrivial accessibility issues was exacerbated by doctoral-level expectations for individual exertion and high caliber productivity. Participants sought their own workarounds or advocated for other solutions frequently, including when inaccessibility was inadequately addressed by accommodations allotted by formal mechanisms (e.g., disability services). Sometimes, participants pursued formal solutions, including escalating issues to the grievance process. However, they largely incorporated solutions that were unaccounted-for as they looked outside of formal channels, asking friends or colleagues, or resorting to problem solving on their own. The accumulation of these efforts amounted to substantially extra time and labor.

4.1 Workarounds and Scripted Solutions Exact A Cost

Participants developed workarounds to address inaccessibility and ineffective accommodations. For instance, when participants received accommodations that were not working, they explored *other additional* solutions—often on their own—to actually address the issue. Participants were used to coming up with workarounds to just get things done, so much so that they were often unaware that their process involved workarounds.

Everything that I do... at this point would be hard to tell you if it's the norm or if it's a workaround that I've made the norm. Um, So, uh, it's a hard question because of that. Because I'll talk to someone, I'll be like oh, it's accessible, you just do this. They'll be like, how did you

know to do that? And then I'd think about it, and I'm like, oh dang, right, I didn't realize that that was a workaround. I didn't realize that I created that method. I didn't realize that I learned how to do that because I couldn't do that. Right, so, it was – I mean, everything that we do, to an extent, is some kind of workaround. -B1⁵

Participants were accustomed to making minor adjustments, trying out approaches until they found useful ones. Minor adjustments for even trivial tasks comprised unaccounted-for effort to manage baseline accessibility needs and occurred frequently due to the nature and intensity of graduate level work, *i.e.*, participants did not incorporate workarounds as one-off solutions, but throughout everyday tasks. A minor adjustment might be memorizing screen reader hotkeys and then allocating extra time to navigate a tool because keyboard-only functions took slightly longer to cycle through. Or, it could be choosing to skip presentations, and reading the paper later, rather than worry about asking for an interpreter on time. As doctoral students, participants were coding, reading, and writing a lot, therefore, these small adjustments were magnified by the sheer amount of research, teaching, and course work. These small tweaks occurred so often, participants melded them into everyday tasks, sometimes unaware that they made any adjustment at all, much less about how much more time it cost them.

I'm constantly feeling guilty about whether I'm taking too long to get things done, and then sometimes I have these moments where like I realize how fast like a sighted person did something. And I'm like, oh my god, like, (laughs) you know, like, okay um, what's something that I just decided I wasn't gonna do anymore. ... I can't remember what it was, but recently I was like, oh I just don't do that anymore. I just ask someone to do it because then I like realized it took me so long. -B5

⁵Some quotes were edited slightly to anonymize past-tense references for participants who graduated or left their programs at the time of the interview.

Table 2: Analytic Themes and Codes for Burden of Survival.

Themes	Codes
Workarounds and scripted solutions exact a cost	<ul style="list-style-type: none"> • The convoluted way I can • Overhead and managing workarounds • Workarounds are not equalizers • Using third party resources • Figuring out on own • Time, effort and delay
Self-advocacy as effort	<ul style="list-style-type: none"> • Advice for others-advocate • Advocacy-advocacy impact • Advocacy from others • How to advocate • Requires maturity and grit • Advocating to educate
Managing social capital for help	<ul style="list-style-type: none"> • Help-tension: Burden with disability knowledge/Experience and asking for help • Tension/Expectation around help and relationships/Credits for expert help • From colleagues/Peers vs. hired help • (Help) with the details • Help for access • (Help) to do the work • Asking for help • Trading help tasks • Paid help • Training the helpers • It feels-burden on others
Graduate school expectations compound time and effort	<ul style="list-style-type: none"> • Study habits and grad life-autonomous • Managing classwork • Managing the pace of grad life • Rhythm of research • It feels-exhausting • Have to be-flexible • Do what I can • Accept setback
Hardship and survival	<ul style="list-style-type: none"> • Managing disability as grad (Exhausting) • System/institutional ambivalence displaces burden of support • “That’s a you problem” • Not/The only one • Dropout • Barrier • It’s my problem • Show what I can do • It feels-overlooked • Imposter syndrome • Isolated

Thus, inaccessibility—and applying workarounds to counter it—was typical and not an exception to the daily routine. Common workarounds for minor issues included trial-and-error attempts to circumvent inaccessibility, programmatically implementing self-coded solutions and scripts, eliciting quick help from colleagues. Oftentimes, participants attempted a fix on their own, and as many of them were strong coders, created their own scripts as a workaround. These kinds of activities constituted “added time and effort,” and was merged into everyday work.

I tried to use all of them. I went through trying Endnote, Zotero, and Mendeley, ...But, [it] ...seemed to like take up too much RAM to use with JAWS and I would read a—try and insert a citation, and it would take like 30 seconds...I wrote like a little script where I could just put in a PubMed ID and it would autogenerate a citation and add it to my library. So that was kind of like the way I got around. -B4

Rather than wait 30 seconds per citation, B4 created their own solution. The time and effort required to create an additional solution to address the incompatibility between the assistive device (e.g.,

the screen reader) and research tool (e.g., reference management application) is additive to the time it took for them to try the screen reader with a variety of tools, endure slow use, and then decide to create the script. Although participants scripted ad hoc adjustments when possible, some of these issues required effort that amounted to “a thesis project in itself”:

Is it worth it to try and make audio interfaces to things like these big websites that have the genome browsing features, and things like that? ... But, I guess [the] biggest problem I’m running into is that’s like a thesis project in itself, and it would be maybe me, and like 3 other people in my field in the country who are blind, so that’s kind of where I am now. It’s like, I can see myself working in projects of that nature once I graduate and can devote time to actually helping the field move forward. But it seems very difficult right now to think of the payoff, I would feel like I was just building this whole big website just for me. -B4

Despite being skilled and resourceful enough to script solutions, not all problems could be addressed by quickly throwing together

an ad hoc solution, and at some point, participants had to weigh the benefits of attempting to solve accessibility issues.

Beyond smaller and seemingly invisible adjustments and scriptable solutions, participants frequently tackled non-trivial issues in multiple ways: trying to fix the problem on their own, going to disability services for a better solution (including seeking adjustment for an allocated accommodation), asking peers for help, hiring free-lance or other student help on their own, or filing a formal grievance. For more substantial issues, participants worked formally through disability services offices to determine what tools and resources they needed, but if those channels were slow or unresponsive, which occurred often, they resorted to informal requests (e.g., asking lab members to describe a graphic in lieu of submitting a request to the disability services office). However, for some participants, prior experience with disability services led them to avoid interacting with the office altogether, even if issues were consequential.

If it was easy to get an interpreter, I would prefer getting an interpreter, but unfortunately it's not. So, I would ask another student for now and I think it's not bad to do it that way because that helps me save time. Also, it helps them be involved in my project and they can get our papers printed. -D3

Prior experience with disability services led to the knowledge that official channels would be time consuming (“if it was easy...”). Rarely, participants escalated larger issues to the manufacturer or institution via a formal grievance process. B2 encountered an issue that could only be resolved by the manufacturer such that they raised the issue with the tool’s company.

I installed [the] new version of MatLab, and then screen reader, it became inaccessible. I tried all the screen readers, I mean, I went to [the] department of IT in our school and they... tried VoiceOver on Mac, JAWS, MAGic, and NVDA on Windows and other commercial screen readers. And it was not access—I couldn't, like, have access to the text box to see what the comments are or whatever...We contacted MatLab, they were rude enough to say, sorry we are not supporting that accessibility stuff... -B2

In B2’s example, we see they first tried—informally, and on their own—ways to solve the inaccessibility issue, by trying other screen readers (not a trivial adjustment, as it could mean fundamentally altering their usual way of using the computer), and also working with the university IT department. With little success, they appealed to the makers of MatLab. These activities comprise a mix of informal strategies, followed by a formal appeal. With the negative response from MatLab, B2 dropped the tool altogether, which also meant losing the benefit of the skills they already had acquired to use MatLab:

I had intensive background in using MatLab, and I had to abandon that... Now, I have started using Python, and I would say that cost me at least two years. That delayed my research because I was easily writing codes on MatLab, but when you change your programming from MatLab to—I mean, changing from Python, for example, to Java is not that problematic. But changing from MatLab to any other language means downgrading. -B2

Admittedly, some issues required more than scripts, and without manufacturer solutions, inaccessibility issues constituted a dead-end; B2 had to accept less-than-ideal Python to continue with research. In these ways, formal channels were undesirable such that

participants sometimes sought other (perhaps just as costly) solutions, because despite back-and-forth communication in the formal process, the situation was not improved. The loss of productivity for B2 was significant and was one example of time and effort lost due to tool incompatibility. One alternative to self-coded solutions would be to pursue legal action and require the tool manufacturers to address inaccessibility, as they were legally required to do. However, legal action could be long and drawn out and was not something participants could wait for while trying to complete research. If a participant had skills to resolve an accessibility issue, regardless of the time and effort it would take, should they? MatLab was a vital tool for B2, so that when it became apparent the tool would not work, B2 needed to try an alternative, no matter the time and effort involved to facilitate the change. For other situations, like those described by B4, minor workarounds might be just enough to get by without involving substantial effort, even if a clear, but time consuming solution could be envisioned. Thus, participants hit a wall with respect to these kinds of workarounds, stopping short of attempting large accessibility fixes or pursuing manufacturer adjustment beyond initial inquiry and instead protecting their research time.

Meanwhile, one avenue rarely attempted was the grievance process, formally filing a complaint with the university stating the inadequacy of an accommodation in pursuit of improved circumstances, or seeking legal action against product manufacturers involved multiple steps. First, participants determined the fault in the accommodation, then made the decision to file a grievance, and then, there could be a drawn out process to follow through. Like attempting major fixes, participants most often prioritized their research and course work and mentioned perhaps pursuing legal action, “after finishing my proposal” (B2), but few had pursued this option at the time of their interview.

I filed a grievance three times, five grievances with [department]. One of the grievances—I finally got a book from one of my advanced statistics classes three months after the class was over. I literally was paying people on my own and doing a number of things in order to have access to it. -B6

Indeed, formal grievance processes were too time consuming and unlikely to directly address immediate needs. Participants could do little with the time and resources they had when accommodations were ineffective. In the more extreme situations, an accessibility issue blocked work, even when formal grievances or appeals were applied (e.g., B2’s experience with MatLab and B4’s avoidance of larger programmatic solutions to address inaccessibility). In addition, we point out that, as doctoral researchers, these larger issues that participants encountered often stressed the systems they were trying to use. The problems participants faced involved cutting-edge research, not simply everyday IT fixes. As a result, participants encountered big problems several times in the course of their work, yet they employed formal options less frequently, and only for extreme circumstances. Participants’ ultimate goal was to get a PhD, and advocating for tool accessibility or ensuring compliance to institutional or legal guidelines could be another full time job.

4.2 Self-Advocacy as Effort

Participants acknowledged that taking responsibility for their accessibility needs meant being proactive in requesting resources,

services, or help. Self-advocacy was a type of effort that participants reported frequently expending to persist for accommodation needs and emerged as individual tasks (e.g., going to see professors before classes started, and throughout the term), and sentiments (i.e., “can’t be shy” or that it was important to be up-front about needs). Self-advocacy was a continuous and ongoing job because there were many issues to advocate for: reporting, describing and explaining inaccessibility in the first place, then agitating when accommodations did not work out, and also to manage bias and personal and professional relationships. These issues were particularly important when collaboration (and individual responsibility to contribute) was an important piece of larger research projects. Participants appealed to disability services, faculty, and other students. Agitating was necessary because the default situation in any scenario was not set up to be accessible or accommodating, and because others did not notice or account for discrepancies.

I think the biggest thing is that you shouldn't be afraid to be proactive and ask for what you need. Other people won't do things to make it easier for you, you need to ask for them yourself and you can also be creative and use phones or other apps (like speech recognition) to communicate. -D2

Thus, advocacy was a big part of managing tasks, because “other people won’t do things to make it easier,” and so the onus was on participants to make clear what they needed. Specifically, participants also advocated for accommodations, but also to demonstrate their own capability, to correct assumptions, and to ensure their grad-school needs were met even after receiving accommodations.

When I came into [professor's] class,... I was in their office hours daily. I mean, daily. I think there's people who thought I had an office in there because I was in those offices going from room to room daily... I would go before class, I would stay after class, I was coming in on the weekends, I got working in a research lab, so that I could then be closer to them, and figure these things out. And what that allowed me to do was to advocate in a different way for myself, that allowed me to not only teach them what I could and couldn't do, but I allowed them to see firsthand what I could and couldn't do and why I couldn't do it. -B1

Several participants commented, as B1 explained, on the need to speak up. Participants recognized that faculty and peers knew little about the disabled experience and so part of requesting adjustments for access needs involved not just informing about what they needed, but also educating others about why accommodations were necessary especially at the graduate level.

People often didn't really know what I could and couldn't do. It was a little bit ambiguous for them, but I really tried my best to show my colleagues and peers what I could do and what worked well for me, and where I might need a little bit of assistance and that sort of thing. But overall, I mean, they were a very... They often didn't know how to help until they got to know me, but they were a very supportive group. -B9

As B9 illuminated, it was rare that participants reported animosity from others, and in fact most reported that faculty, and research peers wanted to help and be supportive. However, there was a difference between helping and presuming a participants’ needs. Self-advocacy also meant clarifying that participants needed access to be able to do things, not just to have issues resolved, necessarily:

I'm constantly learning how to communicate... for example, when I share documents with [others, and] there's like something messed up with the formatting, they'll just kind of fix it. And it's taken me a lot of communication... to talk about, like I'm having access issues. I feel like I need a lot of help, you know, and they just have no idea... -B5

As demonstrated in B5’s example, even with the willingness of others to help, participants spent a considerable amount of time educating others on how to help best, especially because participants needed to balance their competence as researchers versus presumptions that their disability made things difficult to do. Fixing issues without acknowledging the accessibility problem that contributed to the issue would not, in the long run, resolve the issue. For this kind of self-advocacy, participants clarified that inaccessibility did not mean they were incapable, but that there was an issue that prevented access. Thus, advocating meant actively combating being misunderstood or underestimated, and challenging assumptions that led to dismissing concerns from the participants’ experiences.

They didn't know what to do with a blind student in the sciences. And they didn't hear me when I told them how much assistance I really needed and they basically pushed back on me, saying that I was asking for unreasonable accommodations. It became a huge argument to get the assistance that I needed in the classroom teaching. In particular, not necessarily in terms of reading textbooks and that sort of thing, but in terms of the assistance that I needed for teaching... -B9

Like B9, several participants also taught as part of their doctoral experience; such an activity straddled student and faculty roles without being either. It was not uncommon for requests, like B9’s, for an assistant to be judged as unreasonable by those who sanction accommodations. At some point an assumption was made that B9 did not need assistance despite the fact that they felt they needed it enough to ask. By comparison, B5’s experience reveals the informal and nuanced ways that unintended bias may have similar effects: in both cases participants were prevented from gaining the access they desired. In B5’s case, colleagues and others thought they were helping by “fixing” inaccessibility issues rather than addressing the root issues that cause inaccessibility (and would continue to do so). B9’s requests were dismissed because of misunderstanding (“they didn’t hear me”) about how the assistance they sought would help them. In both cases, advocacy was needed to address underlying presumptions about the help that the participant requested. Thus, advocacy required attention to both implied and obvious situations, and involved more than just letting others know what accommodations were needed. Advocacy also involved convincing others of the reasonableness for accommodation in the first place. Participants often contributed this labor (to educate others, to clarify their needs), especially via informal channels even though it did not always result in desired outcomes. Although B9’s request was eventually granted, other participants’ need for human assistants were not (e.g., B2, B5, B12).

When it came to self-advocacy and asking for help or for accommodations, participants admitted they could not be hesitant about requesting help from others. Participants had a particular perspicacity about asking for, receiving, and evaluating help. The type of work they were doing required a kind of vigilance about issues around help: were people “helping” but not allowing the student to do on their own (as in the case for B1)? Or were initial responses

to help dismissing the student's own expert recommendation for support (as in B9's circumstance)? They saw help and advocacy as a part of their role as students with disabilities because they knew that no one else was thinking about exactly what kind of help they might need and because their graduate level needs superseded typical postsecondary accessibility expectations.

4.3 Managing Social Capital for Help

Participants turned to colleagues and peers for help if formal channels were too time consuming or required too much overhead. When participants worked with peers or colleagues for accessibility help, they found themselves managing "the ask," being aware of the social capital involved:

The final proofreader, visual look goes to the sighted person, maybe my assistant, of course, he's an undergrad, so, the problem is that although I need to trust him—but sometimes, you know, my taste is a little bit different—so I don't trust him. And I need someone else, but I cannot ask someone more expert than this, because I don't want to spend their time for such a daunting task, like a senior PhD student, hey come and sit down and fix this visual thing for me. Oh no, that's—that's not good. So that's a weird feeling, you know, how to request people to do a skillful job on that or how to avoid yourself because you're—you want to keep your credits for more serious things that your senior PhDs or your peer PhDs friends can do for you. -B3

As B3 mentioned, often the kinds of help that was needed was specific to graduate-level research or coursework and required expert help. By contrast, human assistants (provided and coordinated by disability services) were often undergraduates, or students without that domain expertise, therefore other PhD students or faculty mentors would be more suitable help. At the same time, participants realized their expert peers and colleagues also had their own research to worry about, and so they were conscientious about asking for help for menial, but non-trivial tasks.

Sometimes I find it burdensome to ask the same one or two friends who I'm comfortable asking, hey, can you do this? Can you do that? Can you do this also? It's not very comfortable to ask this from everybody, and there are people who give you the space to do that, but at the same time you don't want to use up all of it. You want to be cognizant of the fact that they might be busy. And they will not say no, they will do it for you. But, sometimes you just can't. Yeah, I mean, I have this now nice categorization of, this like let me ask my sister, this let me ask my friends. This, yeah, let me ask Aira and just get it done. This, yeah, let me push it off until my undergrad becomes available. So I have like this whole decision that I have to make, who do I ask for help with what? -B12

As B12 remarks, "they will not say no," and most participants reported that colleagues and faculty mentors were usually more than happy to help. However, participants were conscious of overasking colleagues for expert help. Some participants, like B12, managed overasking by having in mind a hierarchy of when to ask for help and from whom. As doctoral students beholden to faculty advisors, committees and peers for accessibility help, participants were keenly aware that they wanted to ask for help judiciously. Part of this consideration for help was because some help may be trivial, but others might require expert focus. Participants wanted to make sure to ask non-expert students, peers and family for help with trivial tasks, and to "save" their asks for expert help for when

they really needed it. In addition to these social considerations, any aspect of asking for help from others also involved some kind of overhead directly related to the intensity of graduate level tasks:

I would say that I probably need to get the stuff finished—at least my first draft—a couple of days, maybe two or three days, before I would if I were just making it, if I was just gonna go show it to someone directly. I can't do the late night, right before-hand thing. I would maybe wanna give someone enough time—I also don't wanna bring it to them at 5 pm the day before — and be like can you look at this when you go home. -B4

As B4 alludes, a key consideration in asking for help was that participants did not want to waste peers' time, knowing that time for graduate students and faculty is limited. Therefore, when asking for help, participants endeavored to ensure they accommodated busy colleagues, including ensuring that help could be beneficial for the helpers as well:

When I needed assistance, making it exciting and good for them as well. That made it really doable and really exciting to me as a blind researcher is to make helping me a rewarding - and I like to help my... I like to think that I helped those who helped me quite a bit as well, but I really want to make it, my goal is to make it a rewarding and wonderful opportunity for all parties involved. -B9

These strategies around help—judiciously selecting who to ask for help with what, endeavoring to be accommodating, and attempting to make help-tasks appealing and beneficial for the helper—required some effort and careful consideration. In addition, participants were aware of being agreeable to peers, senior researchers, faculty advisors and other collaborators, and were sensitive to perceptions that could be influenced by asking for help. If the help issue also involved clarifying the type of help needed, or challenging assumptions about disability that precluded accommodations, or persisting for an adjustment, the effort was undoubtedly multiplied.

4.4 Graduate School Expectations Compound Time and Effort

As shown above, we found that participants employed time, effort and self-advocacy to address inaccessibility and adjust accommodations and included tasks like coding their own scripts and persisting accessibility needs with colleagues. The magnitude and type of effort required to resolve inaccessibility was substantial due to the intense nature of graduate work. The labor involved was additive, and participants managed extra accessibility-related tasks on top of responsibilities that comprise graduate school fundamentals, such as mountains of reading or navigating conference schedules.

I did not really use [disability services] a lot because... for one, every course will have ...maybe about 50 articles to read throughout the course, and then converting those 50 articles to text, the lead time they required was huge, and they would will ask me to send all these articles couple of months in advance ... it was impossible, so I just did it for... two or three journal articles... so it was not really effective for me. -B10

Several participants commented that the magnitude of effort expected of them as graduate students was monumentally more than disability services might anticipate and be able to handle. The lead time necessary to oblige such requests for formal accommodation would ultimately not be worth their while. The typical request for

access to print material or ASL interpretation was exacerbated by graduate school expectations to read hundreds of papers or attend field-specific (and jargon-riddled) presentations and research meetings. Graduate life included many exceptions and extensions of common post-secondary experiences. For example, doctoral students are often expected to attend research conferences and present their work, and these circumstances also present logistical issues:

I look at the conference schedule beforehand, I map out the date of important events and then I send that to a person at [my institution] who will arrange for interpreters at the time. Yeah. It does mean I have to have the conference schedule, but I usually can get that by emailing or contacting the conference to have them be a little prompt with the schedule. -D5

D5's plan depended first on the conference schedule being released in a timely fashion and also that they checked for it. If conference schedules were not posted early enough, D5 admitted, they must agitate for its release to ensure timely request for interpreter coverage. Underlining these issues was the notion that requesting and thus obtaining interpreters (and all minutiae associated with keeping track of when and how to do so) were the responsibilities of the student. However, these responsibilities necessary for securing ASL interpreters at the postsecondary level typically applied to a lecture or presentation as a single course or event. Meanwhile, research conferences are presentation events of a much larger scale with highly specialized domain breadth that also included occasional social and networking hours. Accessibility-related effort did not end with the request, especially if attending a conference:

It can be a bit tough since I don't meet the interpreters until I get there, and sometimes they don't work well with me. There was one interpreter in [conference location] who could not understand me at all, but luckily the other one was pretty good. -D2

In addition to the increased magnitude of work, and the specific nature of participants' research domains, individual relationships with advisors and colleagues distinguished graduate expectations from undergraduate experiences. Further, these different components of graduate school were intertwined, particularly when accessibility issues were concerned. Collaborations meant that the accessibility of shared tools, or logistics of communication, must be accounted for. But, even seemingly isolated accessibility issues could seep into other aspects of student responsibility. We recall that frequently, participants had to adjust to inaccessible tools or solutions, e.g., B2 learned Python because MatLab was inaccessible. The change in programming language was problematic for B2, but such changes also propagated beyond the actual accessibility issue, for example, B12 reported:

These tool changes, they take away from your advisor's productivity as well. Though they are very supportive, they were like it's fine, let's do what's best for you. But, it is going to take away from, you set up a workflow, you're spending his time setting up another workflow, and they are trying to switch, it's not productive. -B12

Thus, the impact on individual PhD students involved managing others, such as student-advisor, collegial and other relationships. Relationship management emerged as an unintended consequence of adjusting to inaccessibility and ineffective accommodations, constituting another aspect of the additional labor that participants contributed. Participants did not want to be an additional burden

on advisors or colleagues. The intricacies of managing these higher-order issues—significantly more papers to read, larger presentation venues, seemingly small programmatic changes that fundamentally altered the nature of the work—were expected as part of graduate work. At the same time, more intense expectations exacerbated accessibility issues.

4.5 Hardship and Survival

In the above sections, we documented how participants engaged in additional labor to informally and formally address inaccessibility, overhead and adjustment for accommodation, and to manage relationships with colleagues and advisors. We showed that this labor exacted costs of extra time and effort on the part of participants and, in the case for informal effort, this labor constituted an integral part of participants' life as graduate students. From unknowingly incorporating workarounds into everyday tasks, to implementing their own scripted solutions and appealing to colleagues judiciously for help, participants acknowledged that they were working in less than ideal conditions. Put together, expectations of graduate student behavior, coupled with inaccessibility, created an imperfect research and learning environment, one that was not created with them in mind.

Because we are living in a world which has not been designed in the way that actually it can be reacting to people's need on time. So, for us, you know,... this is something acceptable. I don't say it is good, but it is something that, I don't just complain to the sky about that, you know? It is something that—alright but I know this is the hassle that I have. -B3

Participants were aware of the expected autonomy of each individual student to find the mechanisms needed to succeed, regardless of accessibility issues as a condition of the graduate school experience:

[graduate school is] totally different simply because grad students are a whole lot more autonomous than undergrad. There's so much you do have to do on your own and pick out things on your own. So you're really, a lot of times, you're guiding your own self. You have an advisor or whatever, but you have to do so much stuff on your own... I still think that might be the biggest part of it, which is they've never had someone totally blind, and I'm a graduate student. -B6

There is a lot that graduate students already handle, with coursework and research; participants approached the extra accessibility work by prioritizing it among their other responsibilities, not—as one might expect—beforehand to make other tasks accessible:

I mean, if I feel guilty at times, like, I get these emails from [disability services] saying, "Hey, there's no test date for this course, can you please let us know," and all of that. And I don't have the time to respond to some emails at times, you're juggling so much already. You just, I don't know, sometimes I do, sometimes I just miss them. I'm like, uh oh, should I have told them? -B12

The degree to which accessibility issues became laborious and time consuming led it to become just another one of the many important and urgent tasks. Participants could have no hope of getting it all done, so they prioritized as they went, often (as any grad student) just too busy to deal with minutiae. At the same time, de-prioritizing accessibility and accommodation tasks could have undesirable consequences. We recall that D5 commented that they needed conference schedules to be posted early enough for

them to schedule interpreters. Indeed, many DHH participants commented on their own failures to manage interpreters, in ways that negatively impacted their experience.

One of the interpreters assigned to interpret for me was not available the week before the presentation so I never got to meet with them but that was partly my fault since I scheduled it last minute. -D2

Failure to schedule an interpreter rested on participants, and regardless of other aspects of interpreter scheduling that may fall through the cracks (e.g., conference schedules were posted late), the implied consequence was that it was their sole responsibility to ensure this important accommodation was addressed if they wanted it. For some it became apparent that such a condition was untenable for an individual to bear:

As a graduate student, I'm supposed to be spending a majority of time on my research. Instead I find I'm spending way more time and energy than I want on managing my "disability"... It's exhausting. What I would like is for like a primer of this exact struggle I'm having. There's actually a paper released in 2018 by Braun, et al. that addresses this at the undergraduate level. I want a paper like this at the graduate level. And I want people to read this. -D7

Participants also bore the cost by taking on guilt for the burden their accommodations may cause others:

But the main concern I have is not taking away something from hearing people. Sometimes a deaf person can feel like a burden. Sometimes if a hearing person changes the way they are doing things to equalize stuff, the deaf person will worry that the hearing person views that as a burden. -D7

Participants developed strategies for dealing with these additional social and emotional considerations. For example, they strategized prioritizing responsibilities and lowered their own expectations:

Scheduling and trying to plan ahead of time and sometimes de-prioritizing things. I mean, yeah, I don't like to do it but yeah, sometimes it is what it is. Yeah you, like some things are not where you want them to be, but there's no time also. So I just take a breathe and let some things go... So yeah, you just do whatever you can and make up for whatever you think is not good about it in other ways that you have control over. Or for example, the slides are bad, give a great talk. Speak really well, so that people don't really have to worry about your slides. -B12

Participants also baked accommodation-based strategies into other everyday tasks, such as developing techniques to ask better questions:

What else can I say about materials? Yeah, you know, A lot of times we would look at videos of lectures that'd be given online or my sighted colleagues had access to a lot of those things. Those were tough, you know, but I always figured out how to ask a question and figure out what they were really about. I prided myself in asking questions at departmental seminars. Really thinking out, okay even if I don't know exactly what this person is talking about, let me try to figure it out at my very best level and then ask him or her a question and make sense of it. -B9

Participants conveyed a variety of attitudes with regard to this extra burden of adjusting to imperfect conditions within which they had to operate, including, like B3, accepting the reality and meeting the challenges of graduate school to create their own success. In contrast, in rare circumstances where substantial effort was made

to meet the participant at the point of access, the outcome was positive.

[the professor] considered it his responsibility to communicate with disability services and get the tactile graphics on time. And like, he worked with [disability services] to share their knowledge that they could anticipate what wasn't going to be accessible and he could talk about what was important that I needed to get out of the material. And so I didn't feel like I had to advocate for myself. I felt like I could actually learn the course material, and it was like, it was like a night and day experience. -B5

Ultimately, though, participants expressed frustration and stress in working within a system that was not created for them and that does not accommodate them. The strategies that participants developed to accept the status quo, to lower expectations, to prioritize their research, and to self-advocate constituted the means by which they survived this extra responsibility. Despite these strategies, participants endured lower grades, subpar access to printed and visual material and presentations (among other things), and longer timelines to complete work, amounting to surviving (perhaps not thriving in) the inaccessible environment they operated within.

... you think you're making good progress, but you realize that you're still behind and it's difficult... It's just—and that's the hardest thing, is to accept. Because nobody wants to be failing, nobody wants the stress of being behind, and knowing that you're graded on the same criteria as everyone else, that you have to meet the same deadline, that you're given less than half of the same access. -B1

The enormous amount of effort participants expended to bridge accessibility gaps as a regular, expected part of their student responsibilities (in formal and informal ways) did not springboard them forward, but barely helped them to meet expectations. With this experience in mind, in anticipation of future careers, participants expressed concerns that the default lack of access in academia made it difficult for them to envision success as professors. For example, several indicated that human assistants—as readers, teaching assistants and ASL interpreters—useful and necessary for their productivity, was not likely to be provided for faculty. Thus, even in future planning, participants conceded the discrepancy in access would influence their career options.

5 DISCUSSION

Without built-in accessibility or effective accommodations, the burden to address complex issues of accessibility at the graduate level falls to the individual, who—as a PhD student—may not have the time or resources to devote to such a project. Participants exerted extra effort to attend to workarounds and needed adjustments, putting in their own time and (often) independent effort, engaging self-advocacy, and managing personal relationships. An expectation emerged for participants that graduate students produce high caliber coursework and research, exerting whatever individual effort necessary, with an implication that *accessibility* was encapsulated within that “individual effort.” From an institutional perspective, students are responsible for requesting and managing their own accommodations [5, 19, 20, 26], and folding accessibility responsibility into individual effort meant that participants effectively absorbed the expectation into regular graduate school tasks [25]—which for them meant producing good research work—rendering the additional labor invisible. We refer to this labor as a *hidden burden*

that participants necessarily took on to survive their graduate experience, but which was unaccounted-for in the general ethos of graduate expectations. The cost of this hidden burden was sustained by the participant in time and effort to ensure their research and educational goals were met, while accepting that the status quo would consistently be inaccessibility.

Drawing on a lens of ableism [13]—discrimination and prejudice based on the notion that nondisabled individuals are superior—we consider that hardship emerged for participants in terms of access that nondisabled students were granted by default, built of a system that presumes nondisabled members [13, 20]. Assumptions of access at the postsecondary level defined expectations and standards that participants were held against [19], regardless of the quality of their accommodations (or the deficit at which lack of access put them to begin with) [35]. These expectations included high quality work, and individual responsibility, as well as emotional and social privileges, such as not worrying about whether accommodations were sufficient or asking others for help. When examined with this ableist lens, the discrepancy between expectations for disabled versus nondisabled doctoral students becomes apparent. Although participants in our study seemed to seamlessly integrate their accessibility-related responsibilities with their research and course related tasks, an ableist lens identifies the default context as inaccessible, further emphasizing the additional burden that participants took on just to meet the baseline at which nondisabled students started [13]. Further, despite legal requirements that students should be provided the same level of access as their peers [26], the barriers to obtaining accommodations could be difficult to maneuver [5] (and thus disempowering [20]), and the accommodations that participants received were typically sub-par by graduate level expectations. This discrepancy was made evident by the time and effort exerted to make scripts, to work around formal accommodations processes just to get things to work, and through the example of the faculty body that indicated to them that similar accessibility issues would persist for disabled faculty. Yet students resorted to additional informal strategies because asking through official channels would take longer than just asking a colleague, for example, all for minimal gain in access; by comparison, we recall B5's positive experience when a professor notably went out of their way to (informally) ensure materials were accessible. Thus, we may conclude that the effort yielded to carry this hidden burden exceeded labor expected of nondisabled students by default and barely helped participants to bridge inaccessibility gaps. Put another way, the infrastructural systems in place, which included formal accommodations, disadvantaged participants from the start, e.g., when DHH students had to check for conference schedules to request interpreters or risk not having any. By contrast, if conference systems and institutions centered the DHH experience, the conference schedule could trigger a request for interpreters. Better yet, conferences could include interpreters in their budgets, in anticipation of DHH participants [27]. Therefore, solutions must involve re-examining and possibly dismantling existing procedures and replacing them with proactively equitable solutions.

What would such an equitable solution look like?

- Disintermediating the connection between students and their helpers may actually save time for overworked,

understaffed disability services offices. Disability services may resist giving *too much* help so as to avoid an unfair advantage to disabled students [26]. Our study shows that there is not a real danger of unfair advantage and that it need not be a major concern for disability services offices. Instead, allowing students to engage their own helpers and supporting that engagement may improve service at a reduced cost in time and effort.

- Educating faculty about the difference between difficulty and inaccessibility [35] may help them help better [32]. Specifically, disambiguating accessibility issues from preconceived (and often ableist) notions of disability could help faculty better understand how they can play a more active role in creating accessible environments conducive to student success.
- Re-imagining formal solutions to center and prioritize the students' experience rather than protecting from a litigious-averse perspective [5]. Participants traded off accessibility issues if it took too much time away from their research work. But, underutilized grievance processes could undermine long term progress and ultimately did not motivate technology companies to make tools more accessible (e.g., MatLab, or screen reader compatibility with references management tools). Restructuring such processes for formal help to be nimble and responsive to graduate student needs may be more useful for students.
- Providing a network of connected resources could help share the labor that computing students expend on individualized solutions and account for lack of institutional knowledge at any one university (a single institution may have few disabled students sparsely enrolled over time). Communities such as the National Federation of the Blind sponsor such listservs [29], but research-level discourse may benefit doctoral students, enabling sharing of scripts and other technical solutions.

For specific technological issues, there exists many opportunities to improve accessibility and ease assistive tool compatibility with research applications. More work is needed to understand specific structural inequities in place, such as interviewing faculty advisors, and investigating how institutional offices and programs work (disability services), etc.

6 LIMITATIONS

This study was focused on a small group of students who identified as blind, low vision, deaf or hard of hearing. We did not interview participants with other kinds of disabilities, and so refrain from making claims as such. In addition, participants' field of interest was in computing or related fields, and so their experiences will be limited to these domains. Although we interviewed blind and low vision and deaf and hard of hearing students, we did not report on differences experienced due to their individual accessibility needs and we refrain from making claims about individual accessibility needs necessarily. Instead, we focused on how participants managed inaccessibility within institutional constraints, applying the lens of

ableism broadly to understand the impacts on the overall graduate student experience.

7 CONCLUSION

We reported on an interview study of 19 disabled doctoral students in computing and related fields. We found that students take on a *hidden burden of survival* in addressing the gap between the inaccessibility deficit they are placed in and the default expectations for graduate students overall. This burden is unacknowledged by the formal processes within institutions ostensibly designed to provide accommodations, limited to a small set of rigidly defined, often inadequate and belatedly delivered accommodations. For participants, extensive workarounds absorbed their limited time, energy, and social capital, yet they absorbed these extra tasks into their regular activities. The need to perform these extensive workarounds constituted a hardship they took on as part of their individual responsibilities to survive the graduate school experience. We acknowledge that institutional structures may have embedded ableist perspectives that put participants at a disadvantage as a default. Recognizing these inequities, and the impacts on student effort, obliges technologists and academics to pursue tangible and proactive changes that could make a difference for student success.

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