# **Navigating Graduate School with a Disability**

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#### **ABSTRACT**

In graduate school, people with disabilities use disability accommodations to learn, network, and do research. However, these accommodations, often scheduled ahead of time, may not work in many situations due to uncertainty and spontaneity of the graduate experience. Through a three-person autoethnography, we present a longitudinal account of our graduate school experiences as people with disabilities, highlighting nuances and tensions of situations when our requested accommodations did not work and the use of alternative coping strategies. We use retrospective journals and field notes to reveal the impact of our self-image, relationships, technologies, and infrastructure on our disabled experience. Using post-hoc reflection on our experiences, we then close with discussing personal and situated ways in which peers, faculty members, universities, and technology designers could improve the graduate school experiences of people with disabilities.

#### CCS CONCEPTS

• Human-centered computing ~ Accessibility

### **KEYWORDS**

Autoethnography; trio-ethnography; hard of hearing; blind; mobility impaired; accessibility; accessible technology; graduate school; computer science education; STEM; engineering.

### 1 Introduction

Success in graduate school is often contingent on community participation, accessing information, and establishing relationships [2,24]. To participate in these activities, people with disabilities may avail various accommodation services such as real-time captioning, in-class scribes, and alternate text formats [59,60]. However, the requested accommodations may not work in many situations due to unpredictability of the graduate school, context-specific nature of the technologies, or incorrect assumptions around their use [36,38]. Through an autoethnography of three graduate students with disabilities (hard of hearing, blind, and mobility impaired), we explore tensions and complexities of cases where the usual accommodations did not work, and the use of alternative ad hoc coping strategies.

Most prior work in inclusive education has investigated singular aspects of graduate school education such as the usability of specialized accessible technologies [16,25,51], the process of requesting accommodations [2,14,23], and the accessibility of specific classroom courses [21,45,53]. Only a few studies have examined the lived experiences of disabled graduate students in the fields of education [38,52] and disability studies [8,47], revealing insights around identity related struggles [8,38], structural and attitudinal barriers to managing work [38,52], and the emotions involved in navigating relationships [47,52]. We contribute to this rare body of work from our unique perspective as computer science graduate students with disabilities, examining the socio-emotional complexities of requesting and using accommodations, and the use of unique *in-situ* technological and non-technological coping strategies in situations of unsuccessful accommodation.

Our research uses autoethnography, a qualitative research method, where the researcher becomes a participant and uses a reflexive account to connect their personal story to broader social and cultural meanings [13,20]. We chose autoethnography as a method to amplify our personal voice as people with disabilities and computer science researchers. While we started graduate school earlier (two in 2018 and one in 2017), the autoethnographic research began in January 2019. To capture a diversity of experiences, we used two

documentation methods. First, using emails and notes to aid recall, we created *retrospective accounts* [18] of our experiences from the beginning of graduate school until January 2019. Second, from January 2019 to October 2019, we created *fieldnotes* [56] of their experiences *in-situ*. We then critically analyzed our recorded experiences using open, axial and selective coding.

Our findings reveal the role of self-image, relationship, technologies, and the institution in creating situations where our regular accommodations did not work (which we term, *mis-accommodation*). We discuss the socio-cultural complexities involved, our feelings and reactions, and the ad hoc coping strategies. We then close with a discussion on how various stakeholders in graduate school (*e.g.*, colleagues, advisors, and department) could start to accommodate these complex situations using tactics such as proactive customization, repurposing existing technologies, and community participation; we name these *in-situ* actions as *uncharted* accommodations.

In summary, our work contributes themes that reveal the tensions in availing disability accommodations from the personal voice of three graduate students with disabilities and their reflections on how graduate schools can implement uncharted accommodations.

### 2 Related Work

We detail models of disability, struggles with disability disclosure, and accommodation strategies of people with disabilities as well as situate our work within inclusive education.

### 2.1 Models of Disability

For many people with disabilities, the degree of physical disability does not determine the choice of accessibility solutions [9,31,37]. To understand what factors affect inclusion, researchers have composed several models of disability [9,58] of which three are relevant to our work: medical, social, and cultural. In the medical model, restoration of the physical sensation (*e.g.*, vision) is the primary focus. Whereas in the social model, the goal is to integrate the individual into the social structure. Finally, in the cultural model which usually applies to the deaf and hard of hearing (DHH) population, a person is viewed as part of a culture or community with common values and practices (*e.g.*, Deaf (capital 'D') culture [32]). Usage of these models depends on the research goals [7,26]. For example, to develop hearing aids and cochlear implants for (partially) restoring hearing, researchers have primarily embodied the medical model [9]. Here, we adopt social and cultural models to examine the interactions of three graduate students with the culture, people, and environment.

## 2.2 Struggles to Requesting Accommodations

In the United States, students in higher learning are required to advocate for their own disability by registering with disability services and requesting accommodations [2,14,23]. While student confidentiality is maintained by disability services [2], the disclosure of disability is daunting due to the negative stigma surrounding one's own disability [41,50] and fears of bias from others [14,41]. The stigmatization may come from past experiences [14,19] such as facing negative attitudes from others [19], or from internal perceptions [12,14] such as feelings of inferiority due to the disability [12]. Non-disclosure is particularly a concern for students with non-visible disabilities (e.g., learning disabilities, chronic pain) whose disabilities may be misunderstood and are likely to pass as non-disabled unless a crisis necessitates disclosure [12]. Moreover, an individual might not view their condition as a disability [9,54]—for example, by holding a narrow view of disability (e.g., not including depression and anxiety [54]) or due to cultural beliefs (e.g., of Deaf community [9]). Even when a student takes the reluctant step to request accommodations, the process itself can be tedious and inaccessible [2]. In this work, we discuss the nuances and tensions of disability disclosure, the reactions of others, and the effect on accommodations from the personal voice of three graduate students.

### 2.3 Accommodation Strategies

Common accommodations provided by the universities include real-time captioning and sign language interpretation for DHH people, in-class readers/scribes and electronically formatted lecture notes for blind people, and accessible classrooms and transportation services for wheelchair users [50,59,60]. However, since an individual's disability and circumstances are highly personal [41,50], these standard accommodations may not work for all situations [36,38]. For example, real-time captioning is not conducive to mobile environments (*e.g.*, when a person is walking to a class) [28], and a scribe cannot be scheduled for sporadically occurring seminar talks—a frequent scenario in graduate school [24]. Moreover, despite assisting the student, the accommodations do not eliminate the impact of the disability [50]. Consequently, the students may adopt ad hoc strategies such as taking assistance from friends [8] or substituting for classes without access barriers [36]. We extend this work by highlighting the unique and personal ways in which the three graduate students dealt with situations where their usual accommodations did not work, and the creative use of uncharted accommodations to substitute some issues.

### 2.4 Inclusive Education

Research in inclusive education has largely examined K-12 education, resulting in changes to pedagogy, school culture, and policy [5,14,33] (see [10] for a historical perspective). However, the structure and type of activities [14,23] as well as the accommodation process [2,14] in pre-college education are much different from graduate school. For example, in K-12, the accommodations are provided without the students needing to request them [2,14].

Only a few studies in the field of education have investigated the lived experiences of graduate students with disabilities using autoethnographic methods [8,38,42,52], revealing the struggles with disability disclosure [42] and disability identity [3,47], the "extra work" done by people with disabilities as compared to their peers to manage graduate school [36], the emotional work of managing reactions of others who may misinterpret their disabilities [38], the socio-emotional aspects of requesting disability accommodations [38,52], and the use of "humor" [38] or help of a "friend" [8] as a coping strategy.

We examine the socio-emotional complexities of requesting and using accommodations, relating to many of the above themes from the unique perspectives of disabled graduate students in computer science, as well as uncovering new themes related to in-situ technological and non-technological coping strategies.

### 3 Method

We provide background on the autoethnographic method, our biographies, and our research methods.

## 3.1 Autoethnography and Trio-Ethnography

Our research uses autoethnography, a qualitative research method in which a researcher becomes a participant and uses "self-reflection and writing to explore their personal experience" and their story to "wider cultural, political, and social meanings and understandings" [20]. Since 1980s, Human-Computer Interaction (HCI) researchers have employed this method at different stages of the design process to inform user study design [29], test a preliminary prototype [26], and as a lightweight method in the iterative design cycle [44]; although until more recently, they were hesitant to publish results from this method fearing negative reactions from peer reviewers [39].

In the past decade, autoethnography has been increasingly adopted to investigate themes such as embodiment [17], temporality [48], interplay between people and things [6], and cultural experience [35]. For example, Lucero used autoethnography to examine the long-term effect of mobile phone detox in his social relationships, work life, navigation, and safety [34], and Jain investigated his longitudinal travel experiences as a hard of hearing individual and connected them to design considerations for personalized travel technologies [27].

In summary, autoethnography investigates the lived experience from within, generating rich personal insights rarely available through other research methods in HCI [15,39]. However, researchers also cautioned against the hegemonic style of meta-narrative found in deeply personal viewpoints [40]. Thus, Norris and Sawyer suggested including multiple researchers (called *duo*- or *trio*- ethnography [7,40]) to gather similar and differing viewpoints on a shared phenomenon, which we also adopt. Through the first trio-ethnography in HCI, we used a collegial conversation to report on our personal stories while establishing reflexivity (through a feedback loop), criticality (by offering different perspectives), reliability (through questioning), and external validity (by verifying anecdotes), the four critical attributes of an autoethnography [13,34].

### 3.2 Biographies

We describe our personal stories as international Ph.D. students in Computer Science and Engineering (CSE). The granularity in the details is based on our individual preferences and comfort.

The first author, *Jain* (www.dhruvjain.info), is a third year Ph.D. student, who is hard of hearing. He has congenital severe to profound bilateral sensorineural hearing loss. His frequency response is from 20Hz to 2000Hz (common hearing range is 20Hz to 20,000Hz), and average decibel loss 75dB. He wears a 'behind the ear' (BTE) hearing aid in both ears. Because he has high frequency hearing loss, high-pitch sounds (*e.g.*, doorbells, high-pitch alarms) are difficult to discern even with the aids. For communication, he relies on facial cues (*speechreading* [57]) and can generally participate well in 1:1 conversation. However, group conversations, and situations with background noise or obstructed faces are difficult.

Jain was born in Delhi, India and grew up in the hearing community. He moved to the US in 2014 to pursue his masters at MIT Media Lab before coming to the University of Washington. He began learning American Sign Language (ASL) in March 2016. Currently, he is level 2 ASL signer. For academic classes and meetings, he uses a real-time, in-person captioner [60], which he only started using after arriving in the US.

The second author, *Potluri* (<a href="www.venkateshpotluri.me">www.venkateshpotluri.me</a>), is a second year Ph.D. student, who is congenitally blind with light perception in one eye. He was diagnosed with optic nerve hypoplasia and nystagmus at three months of age. Though he is functionally blind, use of light perception helps him in perceiving environments, recognizing some objects, and independently playing video games. Potluri was born and brought up in Hyderabad, India in a non-disabled household and a school, but with connections to the blind community. He moved to the US in 2018 to pursue his Ph.D. at the University of Washington.

Potluri is familiar with Braille but prefers to consume content digitally using a screen reader. In India, he depended on digitized course materials when available, and the help of sighted family and friends otherwise. For written examinations which are prominent in Indian schools, he relied on human scribes. In his undergraduate education, he used a combination of human scribes, computer-based tests, and in-person evaluations with professors. Though Potluri received orientation and mobility training in his childhood, he did not use a cane regularly until he moved to the US. Besides cane, he also uses *Aira* [61], an on-call visual interpreter service. Potluri describes his life journey in a TEDx talk: <a href="https://bit.ly/3jhGPQa">https://bit.ly/3jhGPQa</a>.

The third author, *Sharif* (www.athersharif.me), is a second year Ph.D. student, who has quadriplegia (spinal cord injury at the cervical vertebrae 5-6) from a motor vehicle accident in 2013. He is paralyzed from the neck down, has limited control of his arms and hands, and uses an electric wheelchair to navigate. When using a computer, he uses his thumbs to type on the keyboard as well as to operate the cursor pointer on the touchpad; consequently, it takes him comparatively longer to use a computer. He also has difficulty in forming hand postures and finds it challenging, for example, to turn a doorknob or to hold a pen.

Sharif was raised in Karachi, Pakistan. He moved to the US to pursue his Master's at the University of North Dakota in 2012. Due to his car accident, he temporarily suspended his education and spent one year in a rehabilitation facility, before restarting the Master's program at Saint Joseph's University in 2014. Currently, he works as a software engineer at Comcast in addition to pursuing a Ph.D. at the University of Washington.

### 3.3 Data Collection

This project started in January 2019 when Jain's advisor, inspired by a submission at DIS 2018 [34], encouraged the authors to "explore your perspective and journeys as PhD students with disabilities", reflecting on the "socio-technological challenges, and unique opportunities" (email, Dec 2018). Thus, this autoethnography reports on our formative years of graduate school, when we were adapting to the Ph.D. program and the US culture. Our data collection, spanning two years for Jain (September 2017-October 2019, until 2<sup>nd</sup> year of Ph.D.), and one year for Potluri and Sharif (September 2018-October 2019, 1<sup>st</sup> year of Ph.D.) contained two phases:

First, we developed a *retrospective account* [18] of our experiences up to January 2019. These included digital notes of events, experiences, and interpretations constructed from memory in a privately shared Google Doc. Each event records a moment of surprise or tension in graduate school due to the disability and contains a narrative statement of the event, the writer's personal interpretation, emotional valuation, relevant stakeholders, and any accommodations involved. To aid recall, we referred to emails, project notes, meeting memoirs, and event calendars. Second, from February 2019 to October 2019, we recorded *fieldnotes* [56], consisting of notes documented within the week of the event (usually, on the same day) in the shared Google Doc. During this period, following the trio-ethnographic practices [7], we also commented on each other's retrospective account and fieldnotes, relating to the experience, often challenging the assumptions, offering revisioning and alternate viewpoints. This helped us establish *reflexivity* (through feedback), *criticality* (by offering alternate perspectives), and *reliability* (through questioning assumptions). At the end of data collection, the Google Doc contained a total of 69 event reports and 127 comments in 95,468 words.

## 3.4 Data Analysis

We analyzed the Google Doc experience notes and comments using open, axial, and selective coding [11]. At the beginning of the analysis, the three of us read the notes several times and created 18 tentative labels to summarize the data (called open codes) (*e.g.*, social tensions, navigation dynamics). Then, we split, merged, and reorganized the open codes to identify common relationships among them. Through this process, we generated 12 axial codes (*e.g.*, exhaustion from expectations, mis-assumptions around technologies), which were organized into overarching themes (*e.g.*, disability insecurity, relationship tensions). We then selected one core theme that included all our data (struggles with accommodations) and reread the notes to selectively code any data relating to that theme while collecting example excerpts. The theme, codes, and the example excerpts form the foundation of our autoethnographic narrative. Finally, we compared our personal experiences with prior work.

To protect anonymity of our colleagues and to create an open space for transparent self-expression, we followed a closed and private analysis process. However, the later versions of the paper drafts were shared with our Ph.D. advisors for high-level feedback on our research presentation and light editing suggestions. This also helped us establish *external validity* of our documentation as our advisors were stakeholders in many of our reported experiences.

# 4 Findings

We discuss how our self-image, relationships, technologies, and infrastructure in graduate school created situations where our regular accommodations did not work, thus creating *mis-accommodations*. Quotes are drawn directly from the Google Doc experience report and are lightly edited for grammar.

## 4.1 Role of Self-Image

Here, we discuss internal conflicts with our self-identity and its role in requesting accommodations.

We collectively believe that disability is socially constructed [30]; our life experiences and interactions shape how we and others perceive our disability. Moving to different geographical locations (*e.g.*, India to US) and acclimatizing to different societal and cultural norms introduced internal conflicts in our 'disabled' identity,

thus causing a rediscovery of our perceptions, opinions, and needs surrounding our disability. For example, Jain, who is transitioning from hearing to the *Deaf* culture [9], wrote:

"Having been born and brought up in India in a hearing community, I am still not very comfortable with my Deafness and I try to "fit" into the hearing world [...] I struggle with asking for accommodation in cases when it's not provided — out of the fear of appearing rude. Also, as a foreign national, there is this continuous pressure of fitting into the American culture, of appearing friendly, and getting along well with others. Both these [geographical location + cultural difference] lead to constant stress in meetings. As one example, I was there in a last-min scheduled HCI seminar and was not able to understand much (captions cannot be scheduled at the last min). Instead of asking 10 people [present in the meeting] to speak slowly and clearly, I just sat there, pretending to do my own thing, trying to fit in..."

He added: I was not able to understand much in the first place, nor was I able to participate. But then another worry came to my mind: whether people would think that I am ignoring them [...] This led to added social pressure. (Jain, Feb 2018)

This continually changing disability identity led to insecurity while exploring our needs and accommodation requirements, particularly because of the expectations around personal growth in graduate school. For example, when Jain moved into his new office, he faced tensions because he was unable to initially decide which desk to sit at, that works best for his needs:

"I initially opted for a desk that was closer to the door. But then the door was behind me and I couldn't see people coming. So, I asked [the facilities team] for another desk, explaining my reasoning. But that also didn't work out because it was too far from the door. And so, I was feeling guilty whether I should trouble them again, having already asked twice. [...] But, I did. I finally got my desk which is closer to the door, and also allows me to face towards the door. [...] A Deaf person [capital 'D' means a person who follows Deaf culture norms] usually knows that they need to face the door at all times— but since I am struggling with my identity, I am still discovering these things about me. Fortunately, [the department] was very supportive of multiple changes, without questioning. They were very helpful!" (Jain, Jan 2019)

The example above highlights Jain feeling insecure and guilty. Indeed, because of enduring negative stigma around disability over time, we have not yet completely accepted our disabled identities, which sometimes led us to feel ashamed when requesting accommodations.

Interestingly, the acceptance of disability identity varied across all of us due to personal histories, as can be seen from a discussion (Google Doc comments) that followed a weekly research update meeting:

Potluri: Because of access reasons, I chose not to fill in the [optional] slides for the weekly updates meeting. I did not explain why, and she [the group leader] was fine with it. In contrast, in the same meeting when it was [Sharif's] turn, she told [Sharif] that the slides were up on the screen for reference when he [instead] was trying hard to pull them up on his laptop. [...] He has to put in a lot of effort into looking at the screen [(because of limited mobility)] and was using his laptop. Why the difference [in calling people out]? Is it because I take every opportunity to explain my disability and [Sharif] doesn't?

Jain: Between us, it seems, I'm the least vocal about my disability followed by [Sharif] and then [Potluri].

Potluri: This is interesting. My reason for being vocal is after realizing the variety of educational experiences I lost due to me not advocating for myself. [...] My undergraduate university never worked with people with disabilities before. But they assured me that they would give me anything that I would require for me to succeed. But I didn't know what to ask for, and where I knew, I either blamed it on my inefficiency or assumed that me asking for too many things might deter them from hiring students with disabilities in the future. I internalized this notion that I HAD TO set a positive example. As one of the few blind students in computer science, I wanted to prove that blind students are capable of being efficient and producing good quality work.

But [eventually] I realized that I was free to say [about my access needs] and I was not judged. So, I felt I could complain about accessibility and that would be fine. [...] I recognized that accommodations were my right, not a privilege or special treatment." (Jun 2019)

This feeling of inferiority while requesting accommodations, which Potluri faced earlier in life, is an ongoing challenge for Jain and Sharif in graduate school. For example, Sharif said:

"In an attempt to be 'normal', I tried to take notes myself during [my] meetings with [a potential advisor]. [Because of my limited manual dexterity,] the notes are always incomplete and definitely come in the way of having a proper, engaged conversation during our meetings. But it is one of those things that make me feel like the other students. It was also because at the time, I really wanted him as an advisor and wanted to impress him."

He added: "I was, however, pretty content with the fact that whatever [the advisor] drew on the white board, he took pictures and sent them via email. The white board pictures are generally helpful for anyone, but for me, they were especially helpful, which otherwise could easily be a cognitive overload." (Sharif, Jan 2019)

**Summary:** Our experiences show our tensions with culture and self (feelings of inferiority and guilt) in disclosing our needs, and their role in requesting accommodations. Past work also highlights this complexity: people may not always be vocal about their disabilities due to feelings of inferiority or history of facing attitudinal barriers [12,52]. Our experiences extend and contextualize these fears in a graduate school environment and show magnification due to implicit heightened expectations of the graduate school.

### 4.2 Role of Relationship

We detail tensions in accommodations due to complex relationships with our colleagues and the department.

### 4.2.1 Tensions due to interpersonal relationships

Success in graduate school depends on the relationships cultivated with various collaborators [2,24]. Many of those relationships are with people in positions of power, such as with professors, administrators, and senior graduate students. Our experiences show that this power differential caused reluctance in asking for accommodations. For instance, in the example above, Sharif explained how he did not disclose his difficulty in taking notes because "I really wanted him as an advisor and wanted to impress him". Another example relates to Jain being hesitant in asking for captions from a professor:

"[The professor] was kind enough to reach out to me asking if I needed support to discuss [an important] event. [...] Since she was traveling, she offered to call. Calls are hard for me. I was sad that [the professor who knows me well] didn't consider this [...] I wanted her to ask whether I would need a captioner for the phone call meeting. I was more dejected because she was someone whom I respect and look up to a lot, and I didn't want to disclose about captions myself. I feared that this may make her feel bad [for not considering my needs]. Which put me in a tough situation.

But it was important for us to talk [...] So, [after a few days], I informed her that I really would not be able to talk without captions. She sincerely apologized. [...] But, by the time, I informed her, it was too late to schedule a captioner..."

He added: [To attempt an alternate solution,] she suggested using Google Meet [62], an online tool which has an auto transcribe feature. She offered to speak slowly and to type anything that the tool mis-transcribes. I agreed. [...] We had a very good meeting — I was able to understand most of it!

(Jain, July 2019)

This example highlights another common feeling in our experiences: our yearning for *access intimacy* [63]—that is, having high expectations of access—from our 'close' colleagues (*e.g.*, advisors, group members). Another incident which occurred when Sharif was traveling to a conference demonstrates this:

"For the program, [the professor] reserved a wheelchair accessible van for us to travel back and forth from the program activity venues. The van was safe and great, and the drivers were really nice,

and I enjoyed our trips in those vans. But what disappointed me was that the vans were small so we couldn't all sit in the same van (so, there were two vans). The way [the professor] divided us was that in one of the vans me and my personal care attendant (PCA) would [always] sit along with the [same two people from my own university]. I felt really left behind on the opportunity to spend time with the other attendees. The trips were short but it didn't make me feel as much of a part of the group as I would have if it was a larger van that seated everyone. Almost had the feeling of segregation.

I understand that sometimes resources are limited and we have to make do with what we have but I wonder if this was something that [the professor] should have thought about." (Sharif, Apr 2019)

The other students thought that Sharif's expectations from the professor may have been unreasonable, and asked him in a follow-up comment on the Google Doc:

"Jain: Do you think you would have the same expectations if it was someone else other than [the specific professor] whom you know so well?

Sharif: Perhaps not." (May 2019)

Consequently, we considered:

"Jain: Is it okay to have such high expectations of those who are in immediate relationships to us (e.g., advisors)? Doesn't this put an undue burden on them?" (May 2019)

Apart from cases of increased expectations from people in our close circle, we also had cases of low access expectations from the colleagues whom we have not regularly interacted with (e.g., class instructors, department staff) or from those who are not in the accessibility fields. For example, Potluri notes his experience of taking a class:

Well, the Disability Office eventually gave me some resources [in accessible format for the class]; these were optional readings and not the actual slides that were being used for the class. The lack of slides, the extreme intense nature of the course, and maybe a hit to my confidence somewhere down the line, I lagged way too behind in the course. There was no point continuing with it anymore. I was totally upset about the fact that I may have to drop the course. Is it due to accessibility? Is it because I didn't have a sufficient level of prerequisite knowledge? [...] Am I not capable of doing such courses? My mind was in a constant state [...] of stress, self-doubt and shame..." (Potluri, Feb 2019)

Note here that Potluri blamed the disability office and himself but not the course instructor who, he recalls, did not provide the class materials to the disability office in time for converting to an accessible format. He reflects:

"Do I not have high expectations from [the professor] because she is not an accessibility person?"
(Potluri, Sep 2019)

These lower expectations from the responsible parties often caused us to shift the emotional burden and blame on ourselves or other unaccountable parties (e.g., the disability office), leading to feelings of frustration, self-doubt, and misplaced anger.

#### 4.2.2 Tensions in social identity

Besides interpersonal relationships, we also had situations where we had to compromise on our 'social identity' to avail accessibility services. An incident with Potluri, the blind author, details this tension:

"As part of an event, a few CSE students had decided to hangout at the beach. I wanted to go as well. [...] I took an Uber to the beach [...] It was an open event. [As, nobody was particularly [receiving] me, I was worried about how I would find the group once I got there. The event organizer just sent a picture to the event page saying "we found a spot". Ok, I thought I'll just send the picture to Aira (the visual interpreter service) and have the Aira people find the group for me. [However,] when I got to the beach, I became a little anxious. So, I tried to call [a friend] whose phone number I had but she

didn't answer. Probably, because she was in the water. I posted in the event group: "I am at the entrance. Can somebody get me?" I got a text back: "[Knowing] where you are at would help:)"

I wanted to say that I don't know but then, I didn't want to appear as this helpless person asking for help [...] [So,] I opened Aira and called the agent. I explained the situation and asked for help. [...] It was an extremely stressful situation because I had to send the picture of the spot to the Aira agent [that the event organizer posted earlier], and [to upload the picture], I was asked to share my Facebook password because the email wasn't working for some reason. Sharing password with a random stranger! And on top of that [since the app uses the camera to assist with navigation], I was afraid that people might perceive me as a weirdo or pervert taking pictures of people and women! [...] Luckily, I found a few other people who were also looking for the group on the beach. I ended the [Aira] call there.

It once happened before [that] my friend who had low vision was abused by a woman in a bar when he was trying to book his cab. He held a phone in such a way that she assumed he was taking pictures of her. [...] [Thus,] I was afraid. I felt an array of negative emotions." (Potluri, Aug 2019)

This conflict in social acceptability due to use of an accessible technology is reported in past research [41,50], and also faced by Jain and Sharif. For example, Jain's hearing aids sometimes make high-frequency beeps when he configures them which is distracting for people near him. Sharif's state-of-the-art wheelchair is sometimes confused with a robot because of the ongoing research around robotics in our building, leading to people asking uncomfortable questions.

**Summary:** We relate to people with disabilities' access struggles due to power differential [2,14] and social norms [2,23], but also show: (1) how our access expectations increased from 'close' colleagues, (2) how our expectations decreased from people who we do not closely interact with, and (3) how these expectations affected our accommodations.

### 4.3 Role of Technology

We discuss tensions due to misassumptions about the role and context-of-use of accessible technologies.

#### 4.3.1 Misassumption that technology can remove every access barrier

Because of lack of awareness, our colleagues sometimes misunderstood the role of an accessible technology, which led to mis-accommodation. For example, a professor that Jain frequently interacts with incorrectly assumed that the presence of a captioner is enough for accessing embedded videos in lecture slides:

It was [the professor's] guest lecture in today's class. I was really excited. [Immediately before the lecture began] he told me from what I recall: 'I hope your captioner can transcribe my videos. I couldn't have them transcribed because I was asked to send them [to the disability office] a week ago. And I didn't even prepare my PowerPoint slides until yesterday.' I was dumbstruck — my excitement died down and I felt unjust that [the professor] is not willing to provide accessibility for me. Having the captions is just not enough since captioning has a delay [...] It's [also] hard to look at the captioning screen [on a laptop in front of me] and the [embedded] video [in the lecture slides] at the same time..." (Jain, Mar 2018)

Potluri faced a similar issue when professors incorrectly assumed that providing a copy of the lecture slides to him in advance is sufficient to guarantee accessibility. He wrote:

"While I have access to slides, it is hard to understand how and when the speaker transitions through slides. I've observed presenters refer to things on slides as "this" and "that" and use laser pointers to point out interesting and important things on the slide. [...] I miss out on all this information." (Potluri, May 2019)

Fortunately, Potluri was able to solve this need with the help of the in-class reader who informed him about the instructor's current location on the slide deck and other necessary visual information (*e.g.*, figures).

#### 4.3.2 Misassumption that technology can work at all times

The accessible technologies that we rely on (*e.g.*, real-time captioning) are only conducive to specific contexts and use cases (*e.g.*, a group meeting or a lecture [60]) and cannot work in all situations (*e.g.*, when the person is moving [28]). Hence, mis-accommodation occurred when people, including us, expected a technology to work in all situations but it did not. For example, when Potluri joined graduate school, his advisors and him extensively discussed the pros and cons of different word processing software and decided to collaborate using Microsoft Word, which worked best for his needs. However, when he was working on the ASSETS 2019 template, a bug made the comments inaccessible, thus causing tensions:

"I was not able to respond to [my advisors'] comments; the screen reader became unresponsive. It was 11:30PM and I asked for help on Slack. I did not have much time [to finish work]. I just hoped people would respond, and [my advisors] to notice why I delayed sending the document [to not have to be held accountable for the delay] [...] The magnitude of "unexpected" accessibility challenges I face [is huge]. What works one day doesn't [sometimes] work 2 days after. I felt bad that I often ask people to move away from Google Docs to Word [for accessibility] and this [bug] might require [my advisors] to change their workflow again." (Potluri, Jul 2019)

### 4.3.3 Misassumption that technology for one person works for every person

Finally, we observed cases when the accessible technologies for one person were inaccessible to another, thus causing mis-accommodation. For example, Jain and a professor discussed an uncharted accommodation ("talking pillow" [64]), which increased access for him as an hard of hearing individual, but caused a barrier for Potluri, who is blind. As Jain reports:

"I met [the professor] before the accessibility seminar. I told her that captioning does not always work for a group discussion and asked to discuss alternate ways of increasing access. Specifically, I said: (1) delay in captioning makes it hard to follow the speaker transitions, (2) delay in captioning makes it hard for me to join a conversation since I don't know when speaker pauses are made), and asked to discuss alternate ways of increasing access. So, we discussed for a bit and decided to use the talking pillow approach for our accessibility seminar, where we will use objects such as a soft ball or a pen, and only the person possessing the pillow was allowed to talk. This approach made so much difference. The pillow allowed me to (1) visually notice who is speaking and when the speaker transitions occur, (2) prompted people to make pauses between conversations because pillow passing takes time, (3) gave a visual indicator that a DHH person is present in the group, hence constantly reminding them to talk slowly and face towards me. [...]

I was able to follow speakers and [also] more deeply share my ideas and contribute to the conversations. I felt belonged, included, and productive. It was great that I helped shape some discussions!" (Jain, Jul 2019)

Contrastingly, all the visual cues that Jain benefitted from (raising hands to ask for pillow, seeing the pillow being passed) were inaccessible to Potluri:

"While the pillow was really necessary for [Jain], it was causing somewhat of an access barrier for me. [...] I wasn't sure how and when to ask for the pillow as I couldn't see it being circulated around. [Moreover,] for the first few days, I felt intimidated to ask for the pillow, [because] I felt the comment I would [have] to make after getting the pillow would have to be a \*good\* one, worthy of the "attention" from everyone."

He added: "However, I eventually got over it [because] it was an accessibility seminar, a place that makes me comfortable with my disability. Many people missed catching the glove as it was thrown around and so it became a "funny" playful thing where people would laugh if anybody, including me, missed catching. To be honest, a part of me enjoyed the challenge of catching the glove, like everybody else..." (Potluri, Sep 2019)

Another example relates to the use of whiteboards. Jain is hard of hearing and thus benefits when people use whiteboards to explain concepts. Indeed, his advisor, who heavily relies on *visual-thinking* [1], frequently uses whiteboards for project-related brainstorming. But, writing on white boards is inaccessible for Potluri

and thus, in a joint meeting, it leads to issues. For the third author, Sharif, whiteboards are preferred if someone else is writing, but he himself is not able to write if the board is placed too high:

"I could only use only 10% of the white board because of how high it's installed on the wall [of the meeting room]. It was a bit frustrating to wipe off everything continuously to be able to write new stuff." (Sharif, Apr 2019)

**Summary:** Our experiences show complex, unique and deeply personal interplays between our accessible technologies and the various stakeholders, revealing: how conventional technologies created tensions for us (e.g., PowerPoint videos were not accessible to Jain), how our access technologies created tensions for others (e.g., use of visual access technology by Jain caused issue for Potluri, who is blind), how others created tensions for our accessible technologies (e.g., people misunderstanding the role of an access technology), and the use of creative coping strategies.

### 4.4 Role of Institution

Our experiences also emphasize the role of institutions (departments and universities). Overall, we found that our university had great physical (elevators, ramps, open spaces) and organizational (responsive staff members, and disability office) support for access. However, in a few cases, mis-accommodation resulted due to lack of clarity on who bears the responsibility of access among multiple stakeholders (e.g., department, institution). For example, in the following case, Potluri found it easy to get access because there was a single bearer of responsibility (the department):

I was getting coffee [from the CSE kitchen] one day and [someone] from facilities was noticing me. She asked [...]: "we want to make sure you are comfortable using the facilities here." and that was followed by a five minute chat about the things I need: (1) things being consistently placed at the same location, [and] (2) braille labels to help identify the coffee [...] About an hour later, she got back to me telling that the [facilities] team has already ordered the labeler [...] I had an access barrier, and they were [...] solving it. Never did I get [asked] "how do we do this?"

Two days later, I was getting coffee, and I [put my hands] around the coffee pot. And I found the labels! My joy had no bounds! No more tasting tiny quantities of [different] coffees and guessing if this is the coffee I want to drink. [...] A small team approach made accessibility effortless. (Potluri, Oct 2019)

However, when he tried to get the braille labels affixed in a cafe with a slightly complicated ownership, this was difficult:

"Excited from the [above] experience, I sent an email to [the facility member] asking if the [department] cafe could make their menus accessible. She said sure, but nothing happened. I was sad at her. [But,] I later found out that the cafe is owned by another parent body and she might have reached out to them but got no response. [...] I didn't know how to contact [the parent body] and whether they will solve this since [the cafe] is inside the department" (Potluri, Oct 2019)

Another example details Sharif's experience of attending a party, where access was not provided due to unclear responsibility of accessibility:

"After the event, CSE folks organized an after party at [a graduate student's] house, which [I found out] was not accessible. I'm okay if this was just an unofficial event but given that this was advertised using official channels, ensuring accessibility of the venue is an integral part of the event. After pressing hard on the issue, [the student] wrote a description of the accessibility of his house [...] that clearly stated that the hallways are narrow and that the bathroom is not accessible. [Eventually] there was still no change in the venue, and I ended up not going to the after party as much as I wanted to."

He added: "While this can happen at any social event, I expected this to not happen for any school related event. This was severely discouraging, frustrating, and disappointing. I think it's frustrating

because an event like this is where people connect with each other. That's a really important part of graduate life. That's where you make friends. That's where you find collaborators. Otherwise, I am forced to organize things on my own and I can only host a handful of people and obviously only the ones I already know." (Sharif, Dec 2018)

Even though this after party was advertised through the CSE channels, it was a volunteer effort by a graduate student. In such an event:

"Where does the responsibility for access lie? Can the student be blamed for inaccessibility? Should we cancel the event because the only person who volunteered for an after party does not have an accessible place?" (Potluri, in a group meeting with Sharif and Jain, Mar 2019)

**Summary:** In summary, though past work has explored the relationship of people with disabilities with the academic institution [5,33], revealing architectural and policy guidelines [10,33], we extend this work by showing that, regardless of policies, mis-accommodation may result when multiple parties are involved with an ambiguity in who bears the responsibility of access.

### 5 Discussion

As the first *trio-ethnography* [7] in the accessibility community, this paper articulates the tensions and complexities of graduate school from the personal voice of three students with disabilities. We show how conflicts with self-image, relationships, technologies, and infrastructure resulted in situations of "in-access", and how we and our colleagues employed alternative in-situ coping strategies to support access. While past work in inclusive education has highlighted in-accessibility of school pedagogy, infrastructure, and policies [5,10,33,49], our work reveals how in-accessibility *really* happens in the details by highlighting the social-cultural negotiation process and the emotional burden involved. We hope that, using our work, various stakeholders in graduate school (*e.g.*, peers, faculty members, staff) as well as the makers of education technologies and infrastructures can better understand the complexities involved in lives of graduate students with disabilities, and use these insights to design personalized *in-situ* accommodations. Here, we discuss implications from our findings, and the benefits and challenges of using an autoethnographic method.

### 5.1 Uncharted Accommodations

Traditional autoethnographies (e.g., [34]) rarely conclude with a design reflection section. Similarly, our work focuses on systematically analyzing our lived experience and connecting them to socio-cultural implications, which we present in our findings. Still, to encourage and guide universities and technology designers in better accommodating the needs of students with disabilities, we offer our preliminary viewpoints on four ways of implementing uncharted accommodations (*i.e.*, ad-hoc in-the-moment accommodations) below. Since disability can be highly diverse and situational [41,50], we encourage universities to implement these tactics after understanding the needs of their own students with disabilities.

1. Proactive customization: Since graduate school involves uncertainty and spontaneity [36,38], in-situ changes in people's behaviors, technologies, and infrastructure is essential to accommodate diverse range of disabilities. In our case, for example, the CSE staff member accommodated Potluri's needs by affixing braille labels in the kitchen. Similarly, when Sharif was struggling with taking notes, the faculty member took pictures and emailed the notes captured on the whiteboard. Of course, disability-related accommodations are personalized by nature, and are only fully beneficial once the exact needs of the individual are identified. Our graduate school experiences suggest that colleagues and advisors who spend time in building ties as allies of the disability community are not only more empathetic towards the needs of the students with disabilities but also possess more insights on determining possible in-situ accommodations. Thus, we encourage individuals to connect with the disability community and educate themselves on disability-related topics.

We also encourage accessible technology makers to design for contextual needs of students with disabilities. Researchers of applied machine learning have begun exploring in-situ customization of some accessible technologies [22,43]—for example, dynamic find-tuning of hearing aids to varying soundscapes [43].

However, these devices may not work in all contexts (e.g., in presence of heavy noise). Thus, designers should also provide mechanisms for users to calibrate their technologies in the field. For example, the automatic transcription technology (e.g., Google Meet [62]) could allow Jain and meeting attendees to enter in-situ feedback on when the captions are inaccurate, and consequently, prompt the speakers to speak slowly.

**2. Effective collaboration:** Graduate school collaborations can also be carefully leveraged to increase access. Our findings mention cases of how faculty members and students collaborated to accommodate the requirements of people with disabilities. Another interesting example shows how Potluri and his team completed each other's skills while working on a project inherently satisfying his needs:

"I along with two other project members chose to collaborate on a project [related to visual content generation by blind people]. I knew nothing about visual design, aesthetics, or appeal. [One teammate] was great at visual design. Instead of me worrying about it, we complemented each other's skills. He wanted to know more about accessibility, and I learned a thing or two about visual design. Also, I didn't have to worry about how things were [visually] designed at any point; reports, presentations, and even the [paper submission]. There were other small logistical things [the other teammates] did to make working on the team easy. E.g., [One person who had a car] dropped us home if we ended up working late. [...] At 1AM in the night, I don't feel safe [going home alone] and it causes a lot of anxiety. But [here,] I just could focus on work and not worry about how to get home."

(Potluri, Apr 2019)

To ensure people with disabilities can seamlessly disclose their needs, their collaborators should encourage an open and healthy environment. As our findings show, this is particularly important for people in positions of power, as students with disabilities may feel guilty, insecure, or incompetent while disclosing their needs. In one incident, an instructor realized that Potluri may feel uncomfortable in asking for clarifications of visual content. He then encouraged all students in class to interrupt him when needed, thus inherently making Potluri feel safe in calling out if the professor missed describing the visual content (which could be highly intimidating otherwise).

Besides collaborators, people with disabilities should also note that their needs may be highly contextual and may not be immediately understood by colleagues. Thus, communicating about the contextual nature of access and setting an expectation that they will regularly inform them about their needs in-situ, is important.

Finally, in dynamic situations of in-accessibility, whenever possible, involved parties are encouraged to achieve compromise through negotiations. For example, when it was too late for Jain to schedule a captioner for the phone meeting with [the professor], he settled for automatic captions provided by Google Meet, which were not completely accurate. The professor in-turn spoke slowly and offered to type in chat for any required clarifications. While such in-situ workarounds could be useful, we equally emphasize that these are less-than-ideal alternatives for well-planned accommodations and should not develop into a norm. Encouraging communication early and often as possible, as well as promoting and nurturing a culture of routinely checking in with colleagues and planning accommodations ahead of time will reduce the need for last-minute, ad-hoc accommodations.

- **3.** Community participation: Effective participation from the community will also help with in-situ accommodations. For example, when using the "talking pillow", all group members participated to allow Jain to access speaker transitions. Additionally, Jain did not feel that he was being a burden on other people because the group turned it into a playful activity. As Bennett *et al.* [4] argue, successful accommodations inherently involve participation from many people and systems. Thus, universities should think of access as "being and doing together" and not about "getting something done" [4], generating pathways for everyone to contribute in different stages to improve overall accessibility. However, colleagues should ensure that their participation is subtle and respectful so that people with disabilities do not feel guilty of burdening their peers.
- **4. Repurposing technologies:** Finally, our findings show how everyday technologies can be repurposed to support last-minute access needs. For example, in the event where Potluri used the help of an in-class reader

to access the instructor's location on slides, the usage of Mac's iMessage functionality together with the TeamViewer app [65] supported communication *in-situ*. We detail this incident below:

"I was expecting my reader to use my laptop to [scroll through the slides] to tell me which slide to look at, what the instructor was pointing to and [type] any description of videos or demos that were shown [...]. In [an earlier] incident, I realized that my reader wasn't comfortable in physical contact of any kind. This included touching my laptop keyboard. [Thus,] we needed to establish a protocol to communicate in class without her having to touch anything she is not comfortable touching. So, we used iMessage [...]. She would send me messages to go to specific locations [on the slides]."

[Later], I also needed to situate the reader to my current location on the course slides [opened on my laptop] for her to tell me where to go. [So,] we then started using TeamViewer [to allow my reader] remote control to my computer." (Potluri, Nov 2018)

With the myriad of technological possibilities, students with disabilities and their colleagues should continue to explore ways of repurposing existing technologies to solve in-situ needs. Prior research in accessibility details examples of adapting mainstream technologies for access (e.g., [27,46]); however, the repurposing in this work was pre-planned. Future work should continue to explore in-situ technological adaptation.

### 5.2 Reflecting on the Autoethnographic Method

We encourage the accessibility community to report on autoethnographic perspectives to elicit the intimate lived experiences of disability. Because disability is unique to each individual, autoethnographic methods help gather personalized longitudinal perspectives, especially from smaller sample sizes, in varying contexts. Moreover, since disability related issues are often sensitive and personal, autoethnography ensures private and comfortable self-disclosure in the early stages of documentation.

While rewarding, achieving rigor and quality in autoethnographic research requires care. For example, because our research included experiences with colleagues—including those in positions of power—effective confidentiality was key to prevent unintentional disclosures. Yet, first-person research thrives on a high degree of transparency and honesty [15,39]. Thus, we constantly struggled with thinking: "how do we report [our experiences] in a way that we do not end up compromising our academic careers given that our experiences revolve around people who shape our careers?" (Potluri, Oct '19). Even with regular and open communication with our colleagues, tensions existed that needed to be treaded carefully, to ensure that opinions and reputations were valued, and the research remained uncompromised. Fortunately, through trust and support of our advisors, we were able to ensure independent self-exploration in this student-only project.

Furthermore, given the stigma and risks around disability [41,50], we also struggled with the feeling that reporting on our access issues may make us seem incompetent. Specifically, "will reporting on our accommodation issues that cause performance gaps be treated as an excuse for lack of hard work and talent?" (Jain, Feb '20). This emotion was particularly exemplified due to the pressure to succeed in earlier years of graduate school. Fortunately, the three of us are close colleagues and friends, and were able to support and motivate each other through these tensed feelings.

We encourage future autoethnographers with disabilities to take the time to think and communicate what balance between disclosure and privacy makes them and their colleagues comfortable, as well as to ensure a healthy support circle for promoting a generative flow of original thoughts and expressions.

### 6 Conclusion

Through the first trio-ethnography of three computer science graduate students with disabilities, we present the tensions and nuances of requesting and using disability accommodations, and the use of creative coping strategies in inaccessible situations. Using our case as an example, we also motivate the need to, and offer considerations for universities and technology designers to better support the in-situ needs of graduate students with disabilities. In closing, we call out to other researchers with disabilities to contribute their vivid

personal perspectives, thus revealing a diversity of experiences in different educational contexts, potentially using these insights for them and others to design in-the-moment uncharted accommodations.

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