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AN ETHNOGRAPHY OF DISABILITY IN ACADEMIA: STORIES OF CRIP TIME, CRIPPING INDEPENDENCE AND THE COGNITIVE LOAD OF DISABILITY

by

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An Ethnography of Disability in Academia: Stories of Crip Time, Cripping Independence and the Cognitive Load of Disability

Thesis directed by Associate Professor Kathryn Goldfarb

This dissertation examines the experiences of people with disabilities in academia. It is oriented autoethnographically by my own experiences, and those of other students and faculty, to make vivid the phenomenological realities of living on crip time, navigating independence, the cognitive load of disability, and disclosure management. I argue that contemporary policy and practice intend to improve access for people with disabilities, but actually perpetuate the inequities they proport to ameliorate. Ethnographic stories illustrate how living on crip time is constraining in the ableist spaces of academia. The concept of independence has an outsized role in the lives of people with disabilities compared to non-disabled people, and popular discourses of independence shape decision making and impact the well-being of people with disabilities. Disability also adds to a person's cognitive load—the burden of constantly navigating inaccessible places and technologies—affecting a person's well-being and potentially worsening access barriers. While Universal Design for Learning is often represented as a panacea, I argue that it creates a good foundation, but some individualization is still necessary. Throughout, I show how people use a combination of disability expertise and interdependence to creatively navigate inaccessibility and ableism.

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CHAPTER I

INTRODUCTION

I have lived two different lives, one as a sighted child, one as a blind man. In the summer of 1996, when I was 16, my vision started to get blurry. By January of 1997, I could only count fingers with the peripheral vision of my right eye, and my left eye wasn't far behind, meaning I couldn't see anything on the visual acuity chart lit up against the dark wall. Around that time, it was becoming clear that I was a danger to myself and others on the road, and I reluctantly handed over my license to my dad. That made blindness real. Bigger changes were on the horizon. By April 1997, my left eye caught up with my right eye and I was officially legally blind. It was the start of a new life.

When I had normal vision, I was a privileged white kid oblivious to the realities and struggles of people from marginalized backgrounds. I lost some of that privilege when I lost my vision and normal became a memory, like a faded photo that captured a moment in time, a moment I can never get back. I recognize now that in those early years, I wasn't living a fulfilling life in the present because I was drawing on my normative past as if I could somehow return to that time.

This dissertation, oriented auto-ethnographically by my own experiences, as well as the experiences of other students and faculty in academia, examines the experiences of people with disabilities in academia. It makes vivid the phenomenological realities of living on "crip time", navigating independence, the cognitive load of living with disabilities, as well as the various ways that people manage disability disclosure. Overall, I show that contemporary policy and practice intended to improve access for people with disabilities actually perpetuate the inequities they proport to ameliorate. I present ethnographic stories that illustrate how living on crip time is constraining in the ableist spaces of academia (Kafer 2013; Samuels 2017; Davidson and Genshaft 2020). The concept of independence has an outsized role in the lives of people with disabilities compared to non-disabled people, and popular discourses of independence shape decision making and impact the well-being of people with disabilities. Disability also adds to a person's cognitive load—the burden of constantly navigating inaccessible places and technologies—affecting a person's well-being and potentially worsening access barriers. While Universal Design for Learning is often represented as a panacea, I assess the realities of its efficacy through analyzing the discourse and practice of consultants and trainers, knowledge and attitudes of professors, and experiential knowledge of people with disabilities. I argue that UDL creates a good foundation, but some individualization is still necessary. Throughout, I show how people use a combination of disability expertise (Hartblay 2020) and interdependence to creatively navigate inaccessibility and ableism.

I begin this Introduction with a literature review of disability anthropology and its key concepts. Many people who participated in this research feel most disabled at conferences, making it a rich site to introduce major concepts of the dissertation, and I present contrasting ethnographic vignettes about the accessibility of professional conferences. Next, I discuss my research methods and data analysis, which both does the ordinary work of explaining how I did this research, while also showing how I've made fieldwork and analysis accessible for me. I conclude the Introduction with an outline of the structure of the dissertation wherein I introduce my central arguments.

EVOKING DISABILITY WORLDS: KEY CONCEPTS

My research is in line with disability anthropology scholars in the 2020 special issue of *Cultural Anthropology* who have moved beyond medical anthropology and expand their theoretical lenses to include critical disability studies. In their introductory article to that issue, Fay Ginsburg and Rayna Rapp (2020: 5) state: "Historically, anthropological studies of disability were relatively rare until the late twentieth century, often intellectually segregated into the realm of medical and applied anthropology". However, there was a lot of resistance from disabled scholars and medical anthropologists who assert that the subdiscipline of medical anthropology is too narrow to encapsulate disability. Disability anthropology offers a disciplinary and theoretical framework that understands disability as a relational category, whose meaning shifts according to one's intersectional identities, and according to the political milieu (Hartblay 2020; Ralph 2020; Kafer 2013; Lee 2012).

This dissertation is rooted in the concept of disability worlds as developed by Faye Ginsburg and Rayna Rapp in their 2013 annual review article and subsequent book, *Disability Worlds* (2024). In their review, they highlight the importance of bringing disability perspectives to all domains of life because disability is inseparable from all other identities. The concept of disability worlds recognizes the strengths of people with disabilities as creative resources, which moves away from deficit models that characterize people with disabilities as suffering victims. Christine Sargent (2018) adds that disability worlds are multiple and contradictory and exist alongside and within non-disabled worlds. Ginsburg and Rapp write, "The idea of disability worlds offers a framework embracing the challenges and world making that disability brings to social life. This is despite enduring ableism that pathologizes people with disabilities as marginalized or 'suffering subjects.' Instead, we stress how experiences of disability may incite everyday creativity and provoke new ways of understanding human difference in specific locations" (Ginsburg and Rapp 2024: 5).

As I was losing my vision, I was seeking a diagnosis and a cure. It didn't occur to me that I should learn to live with blindness. After all, it felt like just a matter of time, and I'd be cured. I just needed the diagnosis. In April of 1997, I got my diagnosis, Leber's disease. There was no cure, but the promise of science one day finding a cure occupied my young mind. Writing this twenty-seven years later, a cure remains just out of reach, a mirage with the seductive power of a desert oasis. I've come to despise cure talk and its brutal seduction. That kind of hope can hurt too.

A singular focus on cure means that a good life seems impossible if disability is involved. A good future is one without disability (Kafer 2012). As such, financial and emotional resources are dedicated to healing. According to Zoe Wool (2021), good clinical outcomes mean good futures measured by physical improvements and the recovery of abilities. To cure is to irradicate. To overcome is to eliminate impairments. I've lumped these concepts together (curing and overcoming) because they both reject personhood as a possibility for people with disabilities.

Discourses on cure and overcoming disability preclude the possibility of disability as an important part of human experience. It's an ablest perspective that shifts resources from fixing physically and socially disabling environments. A narrow focus on overcoming disability diverts attention from societal and practical solutions to access barriers, and it denies disability and illness as different ways of existing in the present. In *Curative Violence*, Eunjung Kim (2017) develops the framework of folded time, which speaks directly to this point. Kim defines folded time as, "insistence on making the present disappear by replacing it with the normative past, simultaneously projecting onto it a specific kind of normative future" (Kim 2017: 4). Folded time results when the present state of disability seems unacceptable and must be fixed. I argue that discourses of curing and overcoming disability denies personhood to people with disabilities. Personhood requires ongoing reinforcement and recognition by others, but these terms imply that it is simply unacceptable (or impossible) to live a fulfilling life with a disability. For many people with disabilities, these discourses are aspirational, they dangle hope just out of reach, and they encourage pity. People must be fixed. Disabilities must be vanquished.

Further, depictions of disabled people accomplishing phenomenal feats—what is known as the figure of the "supercrip"—can be profoundly problematic in that they encourage both disabled people and the public to adopt unrealistic expectations about what a disabled person can and should do. In *Feminist, Queer, Crip* (2013), Alison Kafer argues that a focus on futurity, wherein disability is not represented, creates endless deferral, thereby maintaining the status quo. The figure of the inspirational supercrip is the ultimate expression of overcoming disability, and Kafer argues that representations of the supercrip are decontextualized and removed from the system of care. As such, the socioeconomic and medical resources necessary to becoming a supercrip are erased, which gives the appearance that everyone has an equal chance to succeed. The supercrip represents a form of cruel optimism. Lauren Berlant (2011) introduced the concept of cruel optimism as the desire for the imagined good life, where the thing one desires is the obstacle to one's happiness. Berlant argues that the current conditions of late capitalism make the good life out of reach. Hence, capitalism functions to prevent marginalized groups from enjoying its bounty, but simultaneously animates the desire for the good life. I argue that the figure of the supercrip likewise motivates people with disabilities to overcome their disabilities which is not always realistic.

Even though I problematize the supercrip, the figure nonetheless does inspire many people. Lorena Gibson (2018) gives us the concept of respair, which is the return to hope after a period of despair. She argues that hope and its associated concepts are effective frameworks for interrogating how people experience the space between possibility and probability. In other words, a supercrip may represent hope to people with disabilities, especially the despair a person may feel after becoming disabled.

The figure of the inspirational supercrip in the media and popular culture is a difficult concept to interrogate analytically because of its various representations. Sami Schalk (2016) defines a supercrip broadly as an inspirational disabled person who has overcome their disability and has accomplished an extraordinary achievement. He argues that the supercrip sets unrealistic expectations for people to overcome their disability, but they also depend on the ablest assumption of low expectations. Additionally, the supercrip is a symbol of the ideology of individualism. The figure makes it seem as if disability can be erased if one works hard enough and ignores societal conditions.

The figure of the superstrong Black mother circulates in ways similar to the figure of the supercrip. According to Cherly Mattingly (2014), the superstrong Black mother is a moral ideal and represents important values that Black women have had to cultivate as survival strategies in a racist environment. However, as an ideal, it may not always be attainable, and failing to become a superstrong Black mother can be internalized as a moral failing. These virtues emerged within the context of slavery and contemporary racism, within which strength was necessary to protect a woman's family and self.

DISABILITY EXPERTISE AND ACADEMIC ABLEISM

In contrast to the powerful tropes of the laudable supercrip, the people who are perceived to have "overcome" their disability, I want to delineate the concept of "disability expertise" (Hartblay 2020). Whereas a supercrip is perceived to have conquered their disability, disability expertise involves becoming an expert of your own disability world. That said, they are not totally separable concepts. In fact, disability expertise lays the necessary foundation in overcoming a disability if that is a person's goal. I suggest that disability expertise is different than overcoming a disability because, in this framework, disability expertise makes living and thriving with a disability possible in an ableist society. Still, these tropes have an outsized impact on societal perceptions of people living with disabilities, as well as on how people with disabilities perceive themselves, as will be apparent throughout this dissertation.

I build on the theory of refusal (Simpson 2014; McGranahan 2016; Reese 2019) by refusing the suffering slot narrative (Trouillot 1991) that portrays people with disabilities as having a deficit. I frame disability as an asset by showing how people with disabilities draw on their subjective disability expertise to creatively navigate inequitable and inaccessible social spaces. Refusals are generative and willful and an agentive response to inequity. Cassandra Hartblay (2020) describes disability expertise as the particular knowledge that disabled people develop to assert agency and self-reliance. People become experts of the disability world that they inhabit. So, for example, my disability expertise is different than another person's disability expertise. We can't live in each other's memories, and we can't wear each other's skin.

Disability expertise is a refusal of objective expertise. Donna Haraway calls objectivity the "God trick": "seeing everything from nowhere" (Haraway 1988: 581). Haraway calls for situated knowledges wherein no single perspective is privileged; instead, situated knowledges are multiple, heterogenous, and always partial, creating a collective subject position. However, western science draws a sharp divide between expert and non-expert, rendering nonexperts incapable of producing knowledge about their own lives. The tension between disability expertise and scientific expertise is an important tension throughout this dissertation.

Within this dissertation, accommodations are a central topic that connects the experience of living with disabilities to individual and structural responses by administrators and instructors in academia. Accommodations create access that make it possible for disabled students and faculty to participate in higher education. Yet, I have found that they are often contested by instructors or are only partially implemented. The access that the people in this dissertation manage to achieve, then, is due to the ways that they creatively use their individual disability expertise.

Institutions of higher learning expect a specific kind of learner, the ideal disabled student who is an expert in assistive technology, as well as someone who can expertly navigate Learning Management Systems and other digital environments like Google Docs, a point emphasized in interviews with Access Coordinators and Alternative Format specialists at three different universities. Collectively, they echoed the sentiment that disabled students are expected to be "experts" in necessary assistive technology before they arrive to school, and students are often expected to be able to independently navigate campus. For example, one Alternative Format Specialist told me in responding to a question about the assistive technology skills required of disabled students entering college: "Students are expected to be the cream of the crop and have mastered the skills needed" (Interview November 2018). I wanted to know if any of the Alternative Format Specialists who I previously interviewed provided assistive technology training for visually impaired students, so I followed up with each of them in separate emails.

Each of them gave similar responses, which is neatly summarized in the following quote. “Potential students to any college or university who are visually impaired should start at an early age in K -12 building their assistive technology and computer skills” (email correspondence April 3, 2019). These standards benefit students with financial and interpersonal privileges but exclude those with multiple forms of marginalized identity. The expectation that disabled students have learned the necessary skills in the K-12 school system assumes that everybody has had the same disability experience.

The Alternative Format Specialists recommend that disabled students get the necessary training through the Division of Vocational Rehabilitation. According to Vocational Rehabilitation counselors, however, they don’t have the ability to make all of their participants experts in any technology. Their mandate is to support people in providing the resources and job specific skills necessary to get meaningful employment that the person and their counselor have planned out. The people I spoke with who qualified to participate in Vocational Rehabilitation told me that the financial and independent living skills they learned are invaluable, but they didn’t learn much about assistive technology.

This focus on technological mastery is, I argue, one form of academic ableism. Ableism is a social system that places value on bodies and minds based around socially constructed ideas of normalcy and productivity. It is a system of oppression that is rooted in anti-Blackness, eugenics, colonialism, and capitalism (Hofmann et al 2020; Freidner et al 2018). To summarize Timothy Dolmage (2017), academic ableism manifests itself when disability is not interrogated as an important part of human diversity with value, when there is a dearth of critical engagement in course syllabi and with disabled students, and when people with disabilities are viewed as objects to be studied, rather than the people who produce knowledge about disability. Academic ableism is present throughout this dissertation. Dolmage explains academic ableism as the desire for higher education to be without disability; in this perspective, certain bodies and minds do not belong in academia. He argues that the oppressive experiences of students and faculty with disabilities is rooted in a structure of academic ableism. Academic ableism manifests in the tenure track process as well, as will become evident throughout this dissertation.

JASMINE: NAVIGATING CONFERENCE ACCESSIBILITY

Allow me to introduce you to Jasmine. Her story enables me to present the major themes that undergird this dissertation—crip time, independence, the cognitive load of disability, and disclosure—in addition to some of my key research sites.

I met Jasmine at a professional conference. Professional conferences are an important part of working in academia. They are a forum for presenting research and ideas and for networking. They are spaces where graduate students transition from amateur to professional, from a student to a junior colleague. It's a liminal space for graduate students, a place betwixt and between (Turner 1969). Professional academics, on the other hand, in their relentless pursuit of recognition, learn to do the dance that will enhance their standing in their particular field. For many disabled people who participated in this research, though, conferences can be a special kind of hell.

People have to travel to conferences, which, in disability worlds, presents its own set of challenges. Unfamiliar hotels in unfamiliar cities with unfamiliar faces can be scary and even lead to embarrassing situations. Without familiarity, there is no predictability. In short, conferences can exacerbate a disability. Unsurprisingly, the majority of people I spoke with about conferences shared comments like, “Conferences are when I feel the most disabled” (Interview November 2019).

Jasmine had responded to my recruitment email requesting interviews with academics who identify as disabled. I was interested in talking to people about their lived experiences as disabled scholars and about their accessibility experience at the conference. Accessibility, broadly conceived, plays a recurring role in this research. Truly, it was my own ongoing digital accessibility barriers I was dealing with that were the genesis of this project. Jasmine was one of the first people I interviewed, and her vibrant strength and honesty lingers in my mind. She’s not apparently disabled unless you pay attention to her step-drag-step-drag gate.

Here's how Jasmine describes her disabilities. She was diagnosed with Juvenile Onset Rheumatoid Arthritis when she was 10 years old. Her contemporary experience of arthritic flare ups is episodic, but intense and can last from weeks to months. It was most active when she was a child and the damage from those flare ups caused lifelong mobility disabilities throughout her body. Her left hip joint is “basically gone”. Sitting and standing are uncomfortable, so she is always alternating. “Carrying my bag around all day and getting around campus fuckin’ sucks” (Interview November 2019). She has accumulated a lot of damage to her hands, so things like typing are hard and painful and take a lot longer for her to do than other people. She explained to me that there are periods of time when she is unable to physically do anything and can’t even get out of bed. These periods of time last 6 months, 8 months, even years when she gets a flare up. Jasmine’s experience indexes the focus of chapter two, crip time. For Jasmine, the quotidian aspects of an academic life are like an athlete forced to compete day after day while severely injured.

Jasmine told me that she's only able to travel to and present at professional conferences because of the support of her partner. Primarily, he carries her materials and assists with opening doors, as well as all of the things people do when travelling to conferences: transportation, hotels, restaurants, and anything else that may come up outside of the conference. Ordinary and mundane for most, they are often impenetrable barriers to her. Jasmine's partner was able to travel with her to this conference, so her primary concern was conference accessibility, which weighted heavily on her mind—the cognitive load of disability, which is the focus of chapter four. Yet despite that weight, her partner's presence at the conference meant she was able to operate independently at the conference. The complex ways people experience dependence, independence, and interdependence are the focus of chapter three.

Since Jasmine has had such bad experiences getting accommodations in her life, she is skeptical when she hears that accommodations will be available. She told me that the only reason she chose to do a poster instead of a talk is that she didn't know if the conference organizers would allow her to sit during her presentation, which is an essential accommodation because she has to alternate between being seated and standing every few minutes to alleviate pain.

At this particular conference, Jasmine was happily surprised with the accessibility support she received. For instance, she requested a chair for her poster accommodation, and they actually gave one to her. Maybe that sounds like a small accommodation, but for a person with arthritis who has a history of being denied even the most basic of accommodations, it was a ticket to an exclusive club. Once at the conference, she reached out to the Accessibility Coordinator and asked for help pinning up her poster. Within minutes, that accommodation was approved too. Two people would be there to help her, and to her utter amazement, the two people were there and did help her. Jasmine explained to me that one issue with accessibility is asking for it and being taken seriously. She said that people who have required accommodations themselves are often more suited to working on accommodations for others because they are more empathetic and more likely to believe people, and this Accessibility Coordinator had several apparent physical disabilities, which Jasmine felt contributed to her positive conference experience. Her story is an outlier though, as most people in this research felt like they had to figure out their own conference accessibility, as in the following example.

On September 22, 2023, I participated in a general board meeting for a large professional section within a major association. The meeting was to address conference accessibility after several members brought their inaccessibility experiences from a recent conference to the attention of the board. In that meeting, the board president said that accessibility is a priority, and they are focused on developing solutions but that it is a burden for the board because it’s a lot of extra work to implement accessibility. He went on to say that they wanted members who needed improved accessibility to provide the board with concrete solutions. Unsurprisingly, the board got strong pushback from members explaining how harmful it is to assume that people who are disabled or who do research on disability have that knowledge. People also expressed their frustration about the implication that their access needs are a burden.

Disabled people are devalued when they are made responsible for their own accessibility. Professors and other leaders deflect their responsibilities back onto the disabled person who needs their support, which is itself a barrier to disclosure, as I discuss in chapter five. The root of much of this deflection is ableist panic, wherein well-intentioned people overreact to reports of inaccessibility by worsening the situation with solutions that sound great but do very little. Importantly, it is one way that people bear the burden of creating their own access needs. This meeting was contentious, and even emotional at times. In the end, board members made promises to do their own research on conference accessibility.

POSITIONALITY: DISABILITY EXPERTISE AS A RESEARCH ASSET

Students with disabilities are often discouraged from studying disability, because researching a group to which you belong doesn't create the "culture shock" moment, long considered an important initiation for budding anthropologists (Kasnitz and Shuttleworth 2004). Additionally, neoliberal austerity actions have cut funding to critical disability studies programs across the U.S.; likewise, scholars with disabilities are at a competitive disadvantage for tenure track employment because of an academic ethos of hyper-productivity (Block 2020). Erin Durban (2021) argues that traditional anthropological fieldwork methodologies themselves are ableist and a major barrier to disabled students becoming professional anthropologists. Durban explains that the cluster of subject positions that define a normative researcher are the ability to be independent, fit, hyper mobile, and the ability to work long hours. Ableism is perpetuated through canonical texts in anthropological methods (like Bernard and Gravlee 2015), in which research design and methods are created with the premise that the researcher is able-bodied.

One way that I've navigated this history, these established norms, is to use autoethnography. In that sense, autoethnography is a method that works toward decolonizing anthropological fieldwork. It's tied to the reflexive turn in anthropology that problematizes the privileging of "objectivity". Roger Lancaster (2011) locates the popularization of autoethnographic methods within the crisis of representation that called into question ethnographic authority in the 1980s. Anthropologists began to recognize that analysis is shaped by their personal experiences and identities. Reflexivity is an intentional act of being transparent about one's own biases that may be rooted in one's positionality (Kondo 1990).

Autoethnography is more than simply telling one's own story; it is a rigorous analysis of one's own experience that relies on the researcher's analytical training and compares those experiences with those described in the literature. In their overview of autoethnography, Ellis et al (2011) describe autoethnography as an approach to research and writing, both process and product. As a blind first-generation white male college student, my own intersectional identity informs the autoethnographic elements of this research. I made my blindness clear in my recruitment emails, and a lot of people were curious about my own disability experiences. Additionally, I connected deeply with many participants with disabilities as we often talked about common experiences.

Anthropologist Robert Murphy's (1987) book entitled, *The Body Silent*, is a key example of autoethnography within disability studies, as he contextualized his disability progression across familial, academic, and health care settings. Murphy describes two key advantages of autoethnography: it reduces the amount of time it takes to establish both trust with the community and an authoritative insider perspective. For instance, a researcher who has never lived with a disability can only write secondhand accounts of disability worlds. Therefore, autoethnography is a powerful tool to write about an insider's lived reality of disability worlds. Certainly, my own blindness was an asset in conducting fieldwork for this research.

This project contributes to the emerging methodology of patchwork ethnography. In her presentation at a 2021 webinar on patchwork ethnography, Megan Moody made the important point that before the Covid-19 pandemic, scholars with disabilities were using digital ethnography and other forms of distant fieldwork for many years, but those methods were not fully embraced until able-bodied researchers utilized them during the pandemic. Gunel et al (2021) call this methodological framework “patchwork ethnography”. By addressing the gendered bias of traditional fieldwork; by creatively using one’s own abilities to conduct research; and by developing a foundation of flexibility, patchwork ethnography works toward decolonizing fieldwork by creating space for people with marginalized identities within the research process.

I have found autoethnography to be an effective methodology to interrogate how academic ableism impacts fieldwork. My fieldwork includes multi-sensory observation, listening, sharing food, speaking, and feeling as through tactile experience: multisensory engagement. My work has been inspired by multisensory ethnography. David Howes (2021) says that multisensory ethnography treats the senses as the object of study and the means of doing research. In his annual review of anthropology, Howes describes a more holistic and inclusive ethnography based in the practice of participant sensation instead of purely passive observation. One of the primary contributions of this review is that the author argues that sensory experiences are culturally produced. Multisensory ethnography is also an effective way to advocate for social justice by including different people’s ways of sensing the world instead of stigmatizing them. In this way, my blindness is a methodological strength.

RESEARCH DESIGN, METHODOLOGIES, AND DATA ANALYSIS

I use autoethnography, interviews, and participant observation to focus on the everyday experiences and interactions of people with disabilities in academia. I present rich ethnographic data at the micro level, which privileges a partial perspective (Haraway 1988). My goal in writing a micro-ethnography has been to create awareness of the phenomenological realities of the lives of people with disabilities. I use narrative storytelling as a writing strategy that brings you phenomenologically closer to disability worlds. Carole McGranahan (2015) explains that narrative draws attention to the messiness of diverse worlds, but also organizes that mess into a comprehensible form. I sometimes use colloquial language as a writing strategy. This dissertation is thus written as a dialogue between me and you, the reader. Lastly, my headings introduce a new topic or theme or research participant with song lyrics or my own poetry or a direct quote from participants. It's a tool I use to set the emotional landscape of a section.

In this work, the administrative structures that shape those interactions aren't at the center of my analysis. In the next phase of my research, I will incorporate into my analysis the macro-level, focusing specifically on the university as an institution, where I will query the neoliberal structures that shape and constrain the capacities of individual actors—faculty, staff, and students—in their engagement with legal regimes like the ADA and culturally salient frameworks like Diversity, Equity, and Inclusion. I will also explore the ways disability accommodations often become invisible, unpaid labor for institutional actors, because of overall lack of funding and support for people with disabilities in higher education. This labor is disproportionately born by women and people of color in academia, and people with whom disabled folks share interdependencies, like spouses.

This research is multi-sited (Marcus 1998), taking place at several U.S. universities, professional conferences in Canada and the U.S., at coffee shops and restaurants, grocery stores, aboard public transportation and Uber rides, at participants' homes, in an independent living center, and via Zoom and email correspondence. Research participants include people living in the U.S. (Arizona, California, Colorado, Washington D.C., Illinois, New Jersey), Canada and Australia. Consequently, the research does not proceed in discreet, site-bounded locations;

instead, the research takes place among disabled people, people who shape the experiences of disabled people (educators, school staff, conference organizers, Vocational Rehabilitation counselors), and incorporates my own experiences in graduate school as a blind student.

I interviewed 73 people for this dissertation. Thirty-one participants responded to my request for interviews because they identify as having a disability. I interviewed five Universal Design for Learning (UDL) experts; five digital accessibility experts; one Vocational Rehabilitation Counselor; 17 faculty or instructors who did not identify as having a disability; eight Disability Services (DS) employees from three universities; four administrative staff at two universities; two instructional design and course support staff.

I was the lead researcher for the Digital Accessibility Office at the University of Colorado, Boulder from 2017-2019. In that position, I conducted a three-year qualitative study on the experiences of low vision and blind students across the academic, digital, social, and physical environments. I have received permission to use the research as part of my dissertation.

I've been conducting participant observation at professional conferences over the course of this project, beginning in November 2019 at the combined American Anthropology Association/ Canadian Anthropology Society conference held in Vancouver, Canada. While in Vancouver, I conducted twenty semi-structured interviews with scholars who identify as disabled. These interviews focused on interviewees' experiences at the conference and in their home departments, social life, and how their disability shapes their everyday lives. At other conferences, I've participated by presenting my fledgling research, and I've attended workshops and panels. As a conference attendee, I was attuned to the content of presentations as well as the accessibility of the physical space and presentation. I also took extensive field notes detailing my observations and lived experiences of conference accessibility. At several of the conferences I attended, I interviewed self-identifying disabled academics about their conference experiences.

In June 2022, I expanded participant observation to include private homes, public spaces, public transportation and Uber, and at an independent living center. The purpose of participant observation was to gain experiential knowledge on the realities of living with a disability and how those realities shape people's educational experiences.

In all participant observation situations, I created voice memos on an iPhone and typed up head notes whenever possible. I spent time each evening compiling these notes into formal fieldnotes (Emerson et al 1995).

Autoethnographic research continued throughout the duration of this project. That part of this project is primarily based on my experiences navigating dissertation fieldwork and associated requirements, such as the Institutional Review Board process and submitting grant applications. My current position teaching for the Continuing Education department was also a fruitful site for me to use an autoethnographic lens.

I recorded semi-structured interviews with people who had consented to be recorded. Interviews and participant observation field notes were coded manually for themes (Bernard and Gravlee 2015). I used a Word document to track codes and their definitions. I copied coded data and then compiled unique codes into their own Word documents from which I analyzed the data for themes. Coding this way takes longer, but doing so makes data analysis accessible for me. Making these data analysis methods explicit is also one way that I contribute to the broader conversation of decolonizing anthropological fieldwork (Durban 2021).

STRUCTURE OF THE DISSERTATION

I develop three major concepts throughout this dissertation: crip time, cripping independence, and the cognitive load of disability.

Things take longer for people with disabilities: they live in crip time. In chapter two, Crip Time, I engage with the term "crip" as a subversive verb and adjective to agitate and destabilize ableist structures (Brown and Lee 2020) and I show how crip time is both agentive and constraining. The ethnographic stories show the daily rhythms of living with disabilities. Crip time is a set of non-normative, potentially creative, and often resistant ways of inhabiting normative time.

In chapter three, Cripping Independence, I show how people with disabilities actually live independently through a combination of interdependent relationships and disability expertise. I use the term "cripping", following Ginsburg and Rapp 2017, to describe "acts of performative intervention that demand changes in exclusionary practices" (2017: 181). I assess the outsized role that the concept of independence plays in the lives of disabled people and draw attention to the ways that people navigate everyday decisions to prevent oneself from being perceived as dependent. The internal pressure to resist the perception of dependence motivates many of the people in this chapter to demonstrate their independence by insisting on doing things themselves.

In chapter four, The Cognitive Load of Living with Disability, I show how navigating a normative world with disabilities adds its own unique stress to a person's cognitive load. My framing shifts in this chapter to attend to the socioemotional stress of living with a disability, from planning everyday activities to using public transportation, from constantly trying to ensure one's own accessibility needs are met to experiencing academic ableism. It's a part of disability worlds that people find difficult to explain but important to understand.

In chapter five, Disclosure, I focus on how people navigate whether and how to disclose hidden disabilities in higher education. I broaden my scope from vision disabilities to include hidden disabilities broadly to demonstrate the generalizability of the concepts I developed in earlier chapters. I present several ethnographic sketches that highlight diverse approaches to disclosure, from those who don't disclose to partial disclosure, to situational disclosure, to people forced to disclose. The chapter also assesses what happens once people disclose, demonstrating both risks and benefits to disclosure.

The Conclusion critiques the idea that Universal Design for Learning (UDL) will eventually replace individual accommodations to create access for disabled students and faculty. Indeed, I urge caution in its adoption and argue that although the transition to UDL will reduce the need for certain individual accommodations, it is not a panacea. Further, I show that UDL consultants inflate its efficacy to gain faculty buy-in. I argue that people want a combination of UDL and individual accommodations because people with disabilities are concerned that the widespread adoption of UDL will result in them losing their individual accommodations, accommodations that UDL can't replace.

Disability is always intersectional, shaped by a combination of a person's positionality (gender, race, nationality, etc.) and the sociopolitical environment in which a person finds themselves. Therefore, we can't assess disability as a category unto itself, as if a person's other identities have no bearing on their disability experience. We cannot yank it out of its unique individual context, but instead, we ought to appreciate disability as an important part of a person's identity. There is little to be gained by creating categories of disability and suggesting that each is defined by x, y, or z. On the other hand, there is much to be gained by assessing time, independence, and cognitive load as they impact people with disabilities across sociophysical spaces. By doing so, we can reimagine access and inclusivity in higher education for people with disabilities.

CHAPTER II

CRIP TIME

I am a crip, a cripple if you prefer. I live on crip time. By invoking it, I am owning it. I'm claiming the word that once oppressed me. It is now mine. I do things differently than you. Is your way always the best way? It takes me longer to do the same task as you. Does your speed matter more than my results? Crip time is an inescapable part of living with a disability. Embracing that inevitability has been an incredible sense of validation in my personal life. More importantly, crip time is a central intellectual concept in this dissertation, as it is for the people who participated in this research.

It is a slur to refer to people with disabilities as cripples, so you may be wondering why I call myself a crip. When I use it, I do so as an act of radical self-empowerment in line with crip activists who use it as a subversive verb intended to agitate and destabilize political, social, and theoretical systems that privilege certain abilities over others (Brown and Lee 2020: Henner and Robinson 2023). It's an act of refusal. Refusal to be marginalized. By making it part of my identity, I rip out its oppressive fangs, rendering it a paper tiger. Any attempt at an insider's perspective of disability worlds must include crip time. My aim here is to offer you that insider perspective.

Crip time is a lens through which to assess ethnographic stories, which illustrate the pervasive ordinariness of living on crip time. By pervasive ordinariness, I mean that you can't flick it on and off like a light switch and it doesn't just happen at work or school. You can't shut the shades and pretend it's gone, and you can't just go faster or work harder. It is not a choice; you can't opt in. Pervasive ordinariness means that crip time is an inextricable part of disability worlds. These stories will show how crip time can be agentive or constraining. Oftentimes, these stories show that it can also be both at the same time.

WHAT IS CRIP TIME?

There is no tidy definition of crip time. Cripping time means that people define it as they live it. Its definition is situationally dependent and unique to each person's experience. That said, crip time impacts everything from daily activities to temporalities of the life cycle. Alison Kafer (2013: 26) explains that crip time involves an awareness that it takes disabled people longer to accomplish a task or to arrive somewhere on time. It emerges from ableist barriers and disability related impairments. Crip time is experienced as the disruption of normative progression through the life cycle (Samuels 2017). Performing adult independence, for instance, may be delayed, partial, or unrealistic. Consequently, the obligations of kinship are also disrupted and rearranged.

Many disabled people I spoke with push back against the obligation to conform to normative time and have turned to crip time as radical self-determination. Crip time is a set of non-normative, potentially creative, and often resistant ways of inhabiting normative time. It is non-normative because it etches the edges of the normate giving shape to disability worlds (Ginsberg and Rapp 2013; 2024). It is creative because it highlights the ingenious ways people with disabilities navigate normative time. Normative time subordinates life lived otherwise; crip time represents a crack within that hegemonic system. Therefore, I understand it as an agentive act of resistance, a generative reimagining of the future and creation of new ontological possibilities for self-determination. By ontological possibilities for self-determination, I mean that refusing normative time opens spaces for other ways of being and, by doing so, normative time is collapsed, becoming one of many ontological possibilities. Being on equal ontological footing empowers people to decide how they live their own lives.

So, crip time is at once struggle and respair, lament and liberation (Davidson and Genshaft 2020). Time is sped up or slowed down, suspended and collapsed, ticking to the metronome of the demands of disabled bodies and minds.

THE SOCIAL CONSTRUCTION OF TIME

Time is a social construct. Time is different across space, throughout human history, religion, economics, and so on. Farmers organize their lives around seasonality, sunrise and sunset, and the weather. Artists work in spurts and according to the vagaries of their creative juices. The majority of people, however, are disciplined into normative time. Normative time differs wherever and whenever you might be. My focus is on normative time in the contemporary United States in the early twenty-first century.

The education system disciplines us into normative time preparing us to transition into capitalist logics of labor time (Thompson 1967). In Foucauldian terms, time is one way that government and educational institutions “take charge of life” to exert power over populations (Foucault 1978). Time, then, is a disciplinary tool of the state. From my perspective, the theoretical glue that binds capitalism, education, and time is Foucauldian biopower. In broad terms, biopower is the control and subjectification of populations through techniques of power in public health, education, housing, and so on (Foucault 1978). In addition to power relations, biopower is concerned with who has knowledge of vital aspects of life and the corresponding truth discourses that emerge, and these two elements (knowledge and power relations) come into being through modes of subjectification in which people work on themselves (Rose and Rabinow

2006). The concept of 'people working on themselves' means that people internalize societal norms and structures and subconsciously seek to emulate societal norms, which often results in more productive populations.

In this dissertation, I assess that process of subjectification in the U.S. education system. Children are supposed to complete one grade level each year. They are expected to be at school on weekdays at a specific time, they have to turn in their assignments on specific deadlines, and children are taught the bell schedule. It's one way that people are socialized into becoming productive citizens. Children are considered to be normal or deviant based upon a standard progression through the education system. Deviance, then, only comes into being by the presence of the category of the normal (Varenne and McDermott 1998). That is, the normal and deviant are mutually reinforcing, requiring one another to exist.

Part of being socialized into normative time are expectations around productivity. Under neoliberalism, people have to demonstrate that they are making something of themselves, which fosters a competitive educational environment dedicated to hyper-productivity, even for K-12 students (Demerath 2009). This means that students are being evaluated on their cultural competence as demonstrated through their success or failure in school. Demerath argues that the U.S. education system is set up as a competition that requires the failure of some children so that others can succeed, converting cultural capital into economic capital, reinforcing socioeconomic inequities. One way that normate society does this is by demanding that disabled people adhere to and discipline themselves into ableist norms of time (Currans 2024). Normative time doesn't recognize the possibility of life lived otherwise.

In what follows, I present three ethnographic narratives to illustrate the lived realities of crip time. To keep this chapter focused, this chapter discusses only blindness.

THE SILENT STALKER

Crip time is not always predictable. It lies in wait, coiled along your trail, striking without warning. People who rely heavily on access technologies are likely to experience crip time in this way, seemingly out of the blue. I'll illustrate this by discussing my own experiences related to access technology.

Access technologies facilitate life in the normative world of digital environments. Understood in this way, assistive technology itself reproduces the boundary between the normal and the deviant. "Notwithstanding their generative power, technologies working within an order of the normal are implicated in the (re)production of the asymmetries that they and it seek to undo" (Moser 206: 374-375). In this framing, technology doesn't remove ableist barriers, it allows people to act competently in an ableist world (ibid.). Once the barrier slips back into place, even if temporarily, I'm shut out of the normative world and back into the world of the deviant.

Becoming proficient with assistive technologies is itself a skill learned over time. For people who lose their vision after learning how to type and use a computer as a sighted person, it can be a slow and frustrating process. You have to rewire the brain. Several people who have been blind since birth, or shortly thereafter, told me that it's easier being born blind than losing vision after having it, primarily because when you lose your sight after having it, you have to relearn how to do everything. One such example is relearning how to use a computer or VoiceOver on an iPhone as a blind or low vision user. If you are born blind, you only learn how to use a computer or phone with these technologies; you don't have to unlearn a skill first. For people who lose their vision after first having it, learning how to become proficient is crip time. Further, even using these technologies effectively entail crip time.

For example, I use the VoiceOver feature on my iPhone, but that's not an efficient way for me to work. To use the keyboard with VoiceOver, you've got to use one finger to slide along the face of the phone until the correct letter is announced; once the letter you want is activated, you double tap the screen with one finger. Slide around until you find the next letter and repeat.

Alternatively, there is a dictation feature. Voice dictation is responsible for a lot of awkward social moments in my life. First of all, it seems to be geared toward standard English. I am from Massachusetts, so standard English is an unreasonable expectation. Some people think I've got an accent. Who doesn't? VoiceOver understands English that nobody actually speaks. As you can imagine, I often have to edit when I use dictation. To do so, I have to hold my finger on the delete key and double tap each character that I want to delete. I've got a bit of finger drift, so when I delete numerous characters, I often end up typing out a bunch of "l's" or "m's". Then I've got to delete those too. I don't always catch my mistakes, so I've sent out several texts that read like I was trying out William S. Burroughs' "cut up method". Unlike Burroughs, the recipients of my texts weren't able to find hidden meanings amongst the jumbled screeds and awkward phrases. Eventually, I started to limit my dictation use to friends and family.

Since VoiceOver isn't a practical way for me to work, I depend on my screen reader program, Jaws. A screen reader is software that converts text to speech, primarily used by people who are blind or low vision. It allows people to navigate and use computers without the use of a mouse. To perform functions normally done with a mouse, screen reader users use a combination of keyboard commands. It's a lot to remember. You can't just glance at the screen or the keyboard to jog your memory. And I can't work without Jaws. Without it, I have no way of knowing what is on my computer screen. Jaws facilitates independence. Independence is thus unstable and precarious, contingent and dependent upon Jaws working properly.

On August 31, 2023, Jaws froze. Time stood still. I had been doing a lot of focused free writing for my dissertation and was ready to start writing actual chapters. Ideas were gushing out. They came to me in my sleep, while making supper, playing with my grandson, or listening to music. I tried to write it all down lest I forget any brilliant ideas. I had momentum. So, when Jaws froze, it was like I was "sinking in the place where I once stood", buried in the rubble of my poser's paradise.[1] I was a painter with no canvas, paint dripping from the brush. When I woke the next day, it was still yesterday morning, and it would be again tomorrow.

In practical terms, I lost writing time, a finite resource that I already stretched thin. I was also feeling a lot of self-doubt and questioning my worth and value. I felt like a hypocrite, like my dependencies tainted my academic success. I dig into these mental health effects of inequity in later chapters, but I point to them here and there to bring attention to the layered impacts that ripple out from crip time.

It took four days to troubleshoot Jaws. My wife spent hours and hours drawing on her vast knowledge, but to no avail. We recruited help from my best friend, who is a digital accessibility expert, but not even our combined knowledge could figure out the problem for those four days. Most troubling to me was that each minute dedicated to helping me was one minute lost for their own work. I can't reimburse those minutes. Their "proximity to disability" (Rutherford 2020)—their proximity to me—meant they experienced crip time along with me. For myself, deadlines remained but I couldn't work towards them.

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[1] Drive By Truckers. 2004. Danko/Manuel. The Dirty South. LP. David Barbe.

In her 2021 article, Erin Durban explains how disabled graduate students are often punished because they can't meet the time-to-graduation requirements. Oftentimes, these students take longer to graduate, may not rack up an impressive number of publications, or miss professional conferences, all of which can stain a person's CV. Since I have a supportive advisor, I don't worry about being penalized for my disability, but it certainly has happened to other students in my research. The neoliberal context of academia is ableist because the emphasis on hyper-productivity excludes people who live on crip time. The crushing demand to publish, write successful grant applications, teach, and complete service work are imposed upon the body-minds of disabled people as they struggle to meet neoliberal timelines of productivity (Brown and Leigh 2020). Academia is a competitive intellectual arena that rewards hyper-productivity. It begins in graduate school and lasts throughout the years of the tenure track process. Interviews for tenure track positions often include questions like, how many articles have you published and how many grants have you received?

Typically, the neoliberal academy is a barrier for people with disabilities, but some people have developed strategies to skirt those barriers and carve out a space for themselves in academia. Sheelagh is one such person.

PROFESSOR SHEELAGH DANIELS-MAYES

I was at a professional conference conducting participant observation focused on conference accessibility and interviewing scholars who identified as having a disability. While walking and joking with a friend on our way to meet colleagues for a drink, we bumped into a woman with an ear bud dangling from one ear. She was flicking and tapping her phone like she was conducting a tiny orchestra, a white cane leaning against the crook of her shoulder. As I passed her, she got my attention, apparently hearing my white cane scrape the sidewalk, so I stopped to say hello. We chatted for a few minutes and set up a time to meet the following day.

Sheelagh is a blind Aboriginal woman. Her university has recently updated its reasonable adjustments policy to include adjustments to workload allocations for employees with a disability or chronic medical condition. The new workload policy was due to a bargaining agreement negotiated by her union. At Sheelagh's university, they have a workload of 40% teaching, 40% research, and 20% service. Under the new agreement, she will be able to reduce her teaching workload by 20%. She has estimated that her blindness adds another 30% to her workload, which creates a real workload of 130%. Under the new policy, Sheelagh's workload will still be 110% of her colleagues' workload after her 20% workload accommodation is applied. Sheelagh chooses to reduce her teaching workload because it's the most sight-oriented aspect of her work.

When Sheelagh first started teaching, her school wasn't prepared to support a blind faculty member. She spent much of her earliest semesters creating her own access. It didn't take long, however, for her to realize that she wouldn't be able to do everything on her own, and although she has a great relationship with the assistive technology specialist on campus, her accessibility needs as a faculty member far exceed his resources. As a result, she developed a plan to hire an assistant, which the university considered to be part of her reasonable workplace adjustments. Her assistant is a graduate student who works ten hours per week doing all of the sighted things that Sheelagh can't do, from digital accessibility to the physical and technological setup in classrooms.

Sheelagh describes her assistant's responsibilities: "A lot of the websites, for example, to upload journal articles or proofread journal articles and what have you are not accessible, or not navigable. They might be accessible according to the guidelines, but when you actually start to navigate them, it's not possible. So, this morning I got the email to approve a journal article, and it just isn't working. I can flick it to her through email and say, here’s what needs to happen. There are things that I can do, like finding journal articles and converting them from PDF to Word, I can do it, but it takes time”.

Sheelagh points to an important tension in the digital accessibility space. Many companies claim their products are accessible because they pass their digital accessibility tester. However, those are only about 30% accurate according to the Digital Accessibility Office at CU Boulder (Interview June 2022). Therefore, many digital products that claim to be accessible are not navigable, and thus, not usable by screen reader users.

Sheelagh is also saying that without her assistant, she spends a lot of time trying to access inaccessible digital spaces. Navigating inaccessible digital spaces and converting documents into an accessible format takes a lot of time. Let’s linger here to consider the time it takes just to figure out how to navigate an inaccessible website, let alone locating and checking the accessibility of articles. It’s important for sighted people to understand what it’s like to navigate an inaccessible website.

Suppose you go to an academic journal’s website to search for articles by a specific author. On the journal’s home page, there are no headings, so instead of being able to quickly scan a page and develop a mental map of it, you’ve got to slog through everything on the page to figure out what’s there. Now, let’s suppose that there’s a list of buttons that you need to choose from, but all of the buttons are labelled as “button”. However, the links are labelled correctly, so you are able to click into the search page where you have to input your institutional log-in information, and you fill out the search terms. You don’t realize that the edit fields are not correctly labeled, so your search comes back empty. You go back through the search terms and find that, for example, the title and author are switched. Correcting the search terms, you locate your article. Navigating inaccessible, or partially inaccessible, websites is a hidden aspect of crip time.

THE RESENTFUL KIND

Some of Sheelagh's colleagues view her accommodations as unreasonable, an unfair advantage. One way they make their resentment known is through passive aggressive comments that she describes as "digs". In fact, they often comment that her assistant works "for" her instead of understanding that she does work "with" her. "But what people don't get is that when you work with someone like that, it takes time as well, because you think about being a research assistant for example, with your colleague, your boss, you've got to sit there and work out the plans and the strategies and all the rest of it. So I have to do that. And so instead of just logging onto a website and clicking here and clicking there and it's done, I have to get her to come in and say, 'okay what we need to do is...' So then we get on the website, and she said, 'Now, what are we doing?' And I'm going, 'okay, so what we need to do is, we need to go here and we need to do this.' And she's got to go through it, and I've got to then. So it takes that extra time" (Interview November 2019). Sheelagh's colleagues either don't understand, or more ominously, refuse to understand that her assistant only does the tasks that Sheelagh can't physically do; she's not Sheelagh's secretary.

Sheelagh's story is so striking to me because it is rare to find a person who has workplace accommodations that take crip time into consideration. People know it's unfair that they are penalized for working slower, but most people I've spoken to tend to internalize societal attitudes and feel they need to overcome their barriers and live in the sighted world. In other words, disabled people often feel like they are the problem, the one with the deficit. Sheelagh, on the other hand, has garnered the support to mold the system at her university to her lived reality. Even so, she can't mold her colleagues' ableist assumptions. The way Sheelagh framed it to me was that she could pretend to be sighted and work every day from six in the morning until midnight, or she could put her foot down and advocate for reasonable adjustments.

Sheelagh demonstrates how crip time can enable agentive action. Her story illustrates how crip time is disability expertise, not only a slowing down of normative time (Saunders 2020). For Sheelagh, the question isn't whether she can do it, the question is whether it is worth the time to do it herself. "Knowledge production inevitably suffers due to the multiple injustices imposed on disabled academics by ableist structures, such as numerous additional hours of unpaid labor" (Brown and Lee 2020). Sheelagh's tenacity is breaking down ableist barriers, urging us to reimagine who is fit for the academic life. Now, I shift stories and introduce you to Dr. Eleanor Mead.

THE STORY OF ELEANOR MEAD

I use theoretical storytelling (McGranahan 2015) to make an argument around crip time. By taking you through various parts of Eleanor's life, I will show you how crip time is part of everything she does. I want to illustrate how all of the smallest everyday tasks are additive, accumulating through the day. Still, as you will undoubtedly come to also see, she is an expert in living on her own time. The timeline has been shuffled so that the stories swirl together into a narrative structure that highlights key scenes that move her story backward and forward, sideways, or in temporal leaps (Narayan 2012).

When I'd ask research participants what they wish people knew about their disability, with varying degrees of colorful language, they would inevitably convey the same message. It takes them more time to do things and they are all too aware that they do things differently than other people. Still, they also expressed confidence in their own abilities to produce quality work as well as anyone else. Eleanor's response neatly captures this sentiment. "I can do just about everything that everyone else can do, I just might do it differently and it might take me longer" (Interview July 2022). This is crip time. Eleanor is saying that *time* is a barrier, not her actual ability.

Eleanor is a blind social scientist who lost her vision during graduate school. Her voice sounds like the first bird song of spring. Her face glows with joy. She speaks with an ease and confidence that welcomes you into her world. When we spoke for the first time, it was supposed to be a quick introduction, and hopefully, to schedule a time for an interview. When she reached me from her landline, we talked like old friends for 30 minutes. Eleanor has a personality as warm as your grandmother's hug.

Eleanor and I are both legally blind, which led to some hilarious moments, as in the first time I met her at her home. We decided it would be easiest to meet in front of her apartment building where she lives alone. It was a perfect plan.

She yelled my name—"Kevin…Kevin…Kevin!"—about a block from where I was standing. For the previous few minutes, I had been pacing up and down the sidewalk, dragging my cane ahead of me, confident I couldn't miss her. Two people were standing in the area in front of the building entrance. Twice they asked me if I needed some help. To them, I must have appeared to be embodying the societal stereotype of the helpless blind person. To be fair, they were watching a blind man walk back and forth for 10 minutes like he was chasing a ping pong ball bouncing between two invisible players. Still, it was degrading.

Once we found each other, we went inside and sat at Eleanor's dining table. She gave me a few plums to enjoy while she prepared some coffee. I asked her to show me around the kitchen and if she could explain how she organizes the kitchen and prepares meals. She invited me to feel the raised dot on the stove to indicate the bottom left burner, which is the only burner she uses. From there, controlling the stove temperature is intuitive. Her oven is an older analog model with a knob to control it, just like the stovetop knobs. To keep things simple, the only other raised dot she uses is for the oven knob. She said that she puts the dot on the 350 degree button because it's the most common setting for her meals. To make her stove and oven safe and functional, all Eleanor needs are two raised dots.

After she explained how she cooks, I wanted to know how she prepared her meals. She opened a small drawer beside the stove and rummaged around, the clinks and tinkling of metal against plastic. She withdrew two small spoons, a worn twisty wire tie on the ½ tsp spoon and nothing on the 1tsp spoon. We moved to the pantry where similar items shared space. Soups on a bottom shelf next to a few boxes of crackers. Fruit cups on a higher shelf alongside a few spices. The marketers out there working to create attractive products have inadvertently helped the blind. The different shapes and textures of food containers, along with the rest of their original and sometimes quirky physical properties, make it easy to distinguish between pantry items. If a person makes a habit of purchasing the same products again and again, they become experts in identifying the product. For Eleanor, it means that she doesn't have to use her handheld magnifier for every single item. That saves her a lot of time.

After my brief tour, we sipped coffee at her dining room table, and she began telling me how she lost her vision. She was born twelve weeks early without a fovea, which is located in the center of the macula on the back of the eye. It's where vision is most acute. However, Eleanor didn't go completely blind until her mid-forties while she was in graduate school.

She explained that she's got one prosthetic eye, and the other one is very blurry with a tiny spot near the bottom right edge of her vision that is less blurry. Eleanor made glasses that emulate her vision so she could show people her visual acuity. I tried them on, but that's like trying out new sunglasses on a cloudy moonless night. So, I handed her back the glasses and she explained that the left lens is totally black as she has a prosthetic eye. The right side is very blurry, and a small portion of the right lens is not as blurry, which is all of her functional vision. She uses her functional vision very well and doesn't use digital assistive technology very much.

Eleanor lost her vision before digital assistive technologies were ubiquitous. Her vision diminished slowly and she learned to use hand-held magnifiers to read printed materials. So even as digital technologies proliferate, Eleanor continues to use physical print and handheld magnifiers as her primary way of accessing documents. In fact, she still uses a landline to make phone calls. She did recently get a smart phone but is still learning how to use it. Throughout Eleanor's story, she described how she navigates a digital world with pre-digital technologies. I draw attention to this to show the diversity of living with vision loss and to make the point that digital technology doesn't always solve access issues for blind people.

What do you wish people knew about your disability, I asked her? "People need to know that blindness is not a prison. We can do pretty much everything that we've always done, but it might take more time and we may have to learn to do it differently". In her response, Eleanor first addresses the stereotype that blind people are miserable and are typically homebound.

Eleanor's point that she can do just about everything as everyone else but slower and in a different way neatly captures a central aspect of crip time. It's a sentiment echoed by most disabled people who participated in this research. Maybe they are slower, maybe they do things differently, but they can do just about everything that you can.

Losing her vision had an immediate impact on Eleanor's doctoral work. Eventually, it led her to change her dissertation topic altogether. Before she lost her vision, she conducted research with an immigrant community close to her school. When she lost her vision, she lost research participants. "Like a lot of communities, there is a stigma around blindness". She explained that research participants just stopped speaking to her, making it impossible to continue her research. As a result, Eleanor changed her dissertation to focus on blindness. Decades later, Eleanor continues to work with blind people. She currently teaches two groups of seniors who are losing their vision. She explained that she teaches everything from the socioemotional aspects of coping with vision loss to important daily living skills.

CRIP TIME ADVENTURES IN INDEPENDENT LIVING

Eleanor was starting to learn to use the screen reading feature on her new smartphone when we met. That feature is called Talkback. Around that time, she was asked to teach her class how to use the accessibility features on their phones, most of which are iPhones. Since Eleanor is still new to the Talkback feature on her phone, she asked if I would help teach a few of her classes because I am an iPhone user. So, we set up a quick phone call to develop a teaching plan and to discuss the logistics of when and where she and I would meet before travelling together in an Uber to the Independent Living Center. As you read this account, think about all the ways crip time appears.

Before I called Eleanor, I spent time brainstorming and developed a lesson plan that focused on the screen reading feature (VoiceOver), and a list of important apps that would help people learn and practice the finger gymnastics of using VoiceOver. When I called Eleanor, she said we have to convince them that they need to learn accessibility first. Most of the people in the group are just starting to lose their vision, so they don't know why they have to learn digital accessibility if they can still see. In the past, there's been a lot of resistance to learning it because it's confusing and frustrating.

While we were talking, Eleanor referenced Siri several times. It's a common misconception among people who don't use VoiceOver, that Siri and VoiceOver are one and the same. Whereas the latter is an accessibility feature, the former is an A.I. assistant that responds to verbal commands. In addition to the VoiceOver feature, Eleanor wanted me to show people how to change the phone background from white to black as an important accessibility feature. She asked about other accessibility issues too, none of which I knew about.

Suddenly, I became aware that I was imposing my own accessibility preferences on people who had different wants and needs than me. I raise this issue to illustrate how the power differential between researcher and participant is always part of the research encounter. I wasn't doing research with the people at the Independent Living Center, but I was doing participant observation with Eleanor. As the researcher, it was my responsibility to bring my skills to bear on the plan outlined by Eleanor, not the plan I thought we needed. Ultimately, I was self-aware enough and caught myself, correcting course before I caused any damage. Beyond my cringeworthy amateur behavior, I want to point out the role of intersectionality in this conversation. Even people with the same disability have different experiences. I created a lesson plan geared towards a blind college student instead of people trying to make their final years livable. Thankfully, Eleanor stopped me from making a mess of it.

The first time we went to the independent living center, I met Eleanor at a bus station. Our plan had been to use a new service for people with disabilities offered by Uber. Eligible Access-A-Ride customers could enroll to take four subsidized, on-demand trips per day, with a maximum of 60 trips a month, directly via the Uber App, with the goal of supporting everyone's ability to easily move around their communities. The website describes the service: "Ride easy. You'll pay the first $2 of UberX or XL trips, and RTD will cover the remainder of the fare, up to $20. You will cover anything additional and will be shown the total amount you owe at time of request". [1]

Eleanor was just beginning to use the Talkback feature for her new Android phone. When that feature is turned on, the traditional finger flicks and taps don't work. There is a different language of swiping and tapping when the device is in VoiceOver mode. Eleanor was using a handheld magnifier in combination with VoiceOver. Squinting through the magnifier and trying to finger swipe and tap with the same hand was clunky and, after 15 minutes of trying, unsuccessful. Ultimately, we took the bus, which meant that we would have a 20-minute walk at the end of the ride. We stepped off the bus and one of the other riders complemented Eleanor's guide dog (Clive hereafter) for his professional behavior on the bus. Eleanor stopped to thank the other rider, and then we were on our way again. It was about 3:00 p.m. on a hot July day. Eleanor was worried about Clive, so we stopped under the shade of a tree every few minutes so Clive could cool his paws from the hot sidewalks.

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[1] Access on Demand Pilot with RTD's Access-a-Ride. https://www.uber.com/blog/denver/rtd-access/. Accessed on September 30, 2023.

After strolling through the manicured grounds of the independent living center to let Clive take care of business, Eleanor reached into her bag to find Clive's treats, but they had disappeared. She spent a few minutes scrounging through her bag while Clive sat anxiously drooling. When she still came up empty, we retraced our steps. She had begun rummaging through her bag as we passed in front of the building, so we stopped there to begin a survey of the area. There we were, the two of us doubled over, scanning through broken eyes, shuffling our feet along the concrete. After a few minutes, we decided serendipity wasn't in our cards. Clive led us into the center, tail between his legs.

The independent living center provides three levels of care for elderly people. There are independent living apartments whose residents require very little care. These residents are often attracted to the social activities of living at the center. Eleanor explained that the elderly can be very lonely living in their own homes. These residents usually have trouble keeping up with household chores on their own, so another thing that appeals to these residents is that the center provides housekeeping and one meal per day. For other meals, residents have a small kitchen. The next level of care is called assisted living. At this level of care, residents require some kind of assistance from bathing and dressing to help with eating or taking medicines. These residents have a studio and bathroom, and their lodging resembles a stereotypical nursing home. The most intense level of care is for people who have recently had a stroke or serious fall. It's the rehabilitation and skills level.

Inside the wide atrium, there's a check-in desk for staff and visitors to sign in. The desk attendant was busy yelling at someone on the phone, so Eleanor tried to sign us in herself. The electronic sign-in system isn't accessible though and Eleanor couldn't quite squint the forms into focus. Once the attendant finished her call, she just waived us through without having us sign in.

As we left the welcome desk, a woman with a mobility walker came over to say hello to Eleanor, who offered to let her pet Clive, telling her his favorite spot is right under the chin. Eleanor introduced us and I asked how the woman was doing. “I haven’t broken a bone in a few months, so I’m mobile right now”. She let me know, “I get a lot of spinal and hip fractures”. While I thought about that, she told Eleanor that she’s been lonely because her husband got moved into assisted living where he would have full-time care. Then, with acceptance only gained through too many deaths, she told us that she lost a brother and then a sister within a few months of each other, as casually as someone talking about characters in a book. She shuffled off telling Eleanor how nice it was to catch up.

Upstairs, Eleanor found a restroom and filled Clive’s water bowl. In the classroom area, she got Clive nestled under the table and began rifling through her bag in search of her attendance sheet. Bag on her lap, magnifier held to her right eye, she pulled out one sheet of paper after another trying to read the title of each in search of the attendance list. After about five minutes, she found it and started chatting with the people who had arrived. Not hearing a particular familiar voice, Eleanor asked them where that person was. She was supposed to get there early this week. “Oh, she died”, one person said. Eleanor returned to her list and asked about another woman, who thankfully, was just arriving.

A few other participants came by seeming more somber than their peers. When someone asked why they were so gloomy, they explained that they had just come from a class on how to prepare themselves and their family for their upcoming death. Death is part of life here.

Impending death, the deaths of friends and loved ones, is an important social context when it comes to learning assistive technology. When people living in an independent living center don’t want to learn assistive technology because they’re not blind yet, it’s different than when a person in their twenties says it. To be blunt, people in the independent living center may die before they go blind, but a person in their twenties may live many years as a blind person. Using this framing, it becomes obvious why there could be resistance to learning digital accessibility by some people in Eleanor's class.

After I introduced myself and explained that I was there to help with some basic smart phone accessibility, someone asked me how to delete people from their contacts app. A second person echoed the same request: we need to get rid of all the dead people in our phones. Seeing the horrified look on my face, the group burst out laughing. I had played into their game; the joke was on me. That's as good an icebreaker as I've heard.

RIDE SHARE

The second time I met Eleanor to assist with her class, she was waiting in an Uber when I arrived. I hopped into the car, and we blasted off from the bus station like only we knew that it was on fire. We sped that way for the entire twenty-minute drive to the independent living center. Once there, I noticed that it took Eleanor a few minutes to gather her things and get out of the car because she had to gather her bag and get Clive situated with his harness and leash and ready to work.

We arrived just before class started, so everyone was seated around the table when we made it to the classroom. This time there was no need for introductions and no tricks to play on the researcher, so we were able to get through a lot of new smart phone accessibility features. On our way out of the center, Eleanor ordered our ride home.

When our driver pulled up, Eleanor asked if the driver would mind dropping me off at the bus station on the way home. The driver explained that she couldn't do that unless Eleanor changed the destination in her Uber request, but Eleanor didn't know how to do that yet. Time ticked, trickling along. I didn't know how to use Talk Back on Eleanor's phone, which was a different brand than mine. I sat, helplessly hoping. After 15 minutes with no success, the driver gave up and agreed that I could just jump out of the car at a stop light near the bus station. Not ideal, but it was the only choice I had.

I include these details from my Uber experience with Eleanor to demonstrate how crip time and Uber time can collide—and the ways that our Uber drivers were, like my wife and friend assisting me with Jaws, drawn into our crip time when we become their riders. I started to think about our amateur NASCAR driver from earlier in a different light. Uber drivers are part of the gig economy, hired to complete a task on demand. Usually, people are hired through a digital marketplace. Uber and Lyft, for example, only pay drivers for miles driven with a passenger in the vehicle not for times they wait for fares. Thus, the idle time an Uber driver incurs by people who take more time at pick up and drop off is uncompensated time.

I've written Eleanor's story as an extended narrative to show you the pervasive ordinariness of crip time. The tasks that you take for granted, that you never think about, are the ones that take her more time.

CONCLUSION

Several blind research participants, like Dr. Eleanor Mead, use guide dogs to facilitate independence. I had been thinking about how much extra time a guide dog adds to a person's day, so Eleanor and I took some time to discuss it. I wondered how often she had requests or comments about Clive and how she felt about those interactions. To me, it seemed like it could add a lot of time to a person's day. So, I wasn't surprised when she told me that nearly every time she leaves her home, someone asks to pet Clive or stop her to offer a comment about him. Then, there are the minutes that add up from caring for Clive. Despite all of the extra time it takes to use a guide dog, Eleanor told me that it's completely worth the time.

Caring for Clive is crip time. Clive facilitates access to society, creating opportunities to develop relations with people. Guide dogs can make life livable. A guide dog creates a material connection that makes full personhood possible in an ableist society. Donna Haraway's (2016) exquisite concept of "becoming with" neatly captures the relationship a blind person has to their guide dog. The concept of "becoming with" is a way to explain how different species "become who and what they are in relational material-semiotic worlding" (Haraway 2016: 13). Put differently, a guide dog can only be so if it has a human companion. It is otherwise only a dog. "Becoming with", then, is a framework with which to understand how the human and the dog are separable but engage in an ongoing relational process that informs who they are and what they do. Those in proximity to disability—my wife, our Uber driver, Clive—are part of this material-semiotic network of relationships that are also relationships with time.

Normative time is a hegemonic system wherein crip time is subjugated. Still, we've seen how people like Professor Sheelagh Daniels-Mayes have drawn upon their disability expertise and crumbled the cracks of the hegemonic system. There's space for crip time to exist alongside normative time. Indeed, equity and inclusion are only possible for people with disabilities by making space for crip time. I've shown how crip time is constraining in ableist spaces, limiting the ability of disabled people to adhere to neoliberal timelines of productivity. I've likewise illustrated how people expertly navigate crip time in a world that operates on normative time. These relations of time are also relations of independence, dependence, and interdependence, as I explore in the following chapter.

CHAPTER III

CRIPPING INDEPENDENCE

In this chapter, I argue that popular discourses of independence shape decision making and the well-being of people with disabilities. The concept of independence has an outsized role in disability worlds (Ginsburg and Rapp 2013, 2024) compared to the world of non-disabled people who may not think about independence very often. People use disability expertise to live independently while simultaneously showing how everyday decisions are made to prevent oneself from being perceived as dependent. It is this creativity in drawing on disability expertise to live independently, that I call "cripping independence" (Ginsburg and Rapp 2017).

Even though interdependence characterizes the social relations of all people, for some people their interdependencies are more obvious (Buch 2018: 19). Interdependence dissolves the binary between dependence and independence. As a conceptual framework, interdependence allows us to learn how those who require care or who have been labelled as dependent, contribute to their relationships and to society. A disability studies approach to interdependence recognizes that we move in and out of dependence through the life course, meaning that we are all subject to the vagaries of health and illness and the corresponding acts of caring and being cared for (Taylor 2014: 109-110). Interdependence, then, is an acknowledgement that we all rely on others, both human and non-human, throughout our lives (Buch 2018). Interdependence is an important way that people crip independence (Abrams et al 2024).

Although we rely on others, human and non-human, within disability worlds a key question is whether and how to accept or reject social affordances. Social affordances, as defined by Arseli Dokumaci (2019), refers to the tools created from objects and people that disabled people utilize to make physical environments livable for them. Dokumaci engages with the concept of affordances to develop the framework of "care intimacies". "Care intimacies" describes how the care needs of a person can be met through intimate and unspoken acts as people become affordances. Importantly, Dokumaci connects this concept to perceived dependence, arguing that people who try to live up to the ideals of independence through overpassing as able bodied and hiding their disability, often forego affordances. I argue that foregoing affordances in this way is an example of the internalization of ideologies of individualism. Put simply, to reveal that you need an affordance is to admit that you have not been cured and you have not overcome your disability.

Independence is as much of a feeling as it is a subject position. That is, people can feel as if they are being dependent when they accept assistance of any kind, even if they live independently. Independence isn't a ribbon you can pin on your shirt, it's a contested space in the psyche that requires constant vigilance. It's the feeling of independence that I want to address in this chapter, connected to the concept of embodiment and habitus, habitual tendencies that guide the ways a person will act in a particular situation (Bourdieu 2002). Habitus is the behaviors, language, and mannerisms of a person—reflections of that individual's specific past that have been engendered through the norms and customs of that individual's social space. I want to emphasize the degree to which independence is an omnipresent part of life for people who participated in this research—such that attitudes surrounding independence become a type of habitus, as we will see over the course of the chapter.

How do my interlocutors with physical and cognitive disabilities articulate how they felt about independence?

"It's the ability to do what I want and need to do without having to explain to others why I do things the way I do" (Interview November 2019).

"It's oppressive, a trap! It's an expectation that I can't meet" (Interview November 2019).

"Independence means living interdependently" (Interview July 2022).

"Independence means living interdependently and not being shamed for it" (Interview November 2019).

"It's the ability to do stuff on your own" (Interview December 2019).

"Independence is a communal effort" (Interview June 2022).

There are both commonalities and differences amongst these individuals. Several people make claims on independence as an outcome of interdependent relationships. Other people imply interdependence by saying they don't want to be shamed or have to explain why they do things the way they do. Whether explicitly or implicitly, habituated sensibilities about the concepts of independence, dependence, and interdependence shape how these people operate socially, bodily, and cognitively in the world. I argue that my interlocutors also use the concept of interdependence to stake out a space of resistance: they crip independence.

THEORETICAL AND HISTORICAL FRAMEWORKS

Defining independence is fiddly. The trope of independence is so deeply engrained in American life that its definition feels obvious, yet its exact meaning is contextual wherein certain elements are emphasized and others fade, only to return to prominence in the next instance. The ethnographic stories I present in this chapter will vividly portray how independence is enhanced or diminished according to who is involved and according to what is going on and where it is happening. Further, the concepts of independence and dependence in the United States are co-constitutive cultural categories (Gal 2002). They are not particular ways of being, nor are they antipodal concepts; rather, they are indexical symbols that shift (Verscheuren 2000) according to the referential context of their usage. The very introduction of one category automatically creates its opposite. Dependence can only come into being as a cultural category once independence becomes a category, and vice versa.

Rather than a universally applicable definition, then, when I refer to the trope of independence, I am referring to a set of beliefs, attitudes, and discourses ubiquitous in the contemporary United States, which, I argue, are rooted in capitalist ideologies—specifically, the values of individual responsibility that define a citizen's role under capitalism and neoliberalism. In his article on stigma and Autism, Roy Grinker (2019) explicitly ties stigma around mental health to capitalism and ideologies of individualism. The ideal of the modern worker within a capitalist system is one who is autonomous, self-reliant, and personably responsible. In other words, individual responsibility is a neoliberal form of independence that prevails as the dominant western social attitude about dependence. People who do not conform to the ideal modern worker tend to be stigmatized. From the perspective of a disabled person, resources that allow "independence", like social security and disability benefits, are marked by others as signs of "dependence" in the United States and produce a stigmatized positionality (Fraser and Gordon 1994). The transition to industrial capitalism in the U.S. excluded people with disabilities, which had the effect of segregating people with disabilities into a class of dependents (Rose 2017). Unable to contribute economically to the family, they became a burden to the family because they used familial resources. Families lost their capacity to care for disabled kin and their ability to make use of at least partially productive disabled family. "The sharp division that employers and, to a lesser extent, labor unions began to draw between 'productive' workers and people with a wide variety of disabilities at the turn of the twentieth century limited disabled people's access to paid work and, thereby, their ability to sustain themselves and their families" (Rose 2017: 111-112). Rose argues that disability and dependence became synonymous, and, therefore, the corresponding attitudes that people with disabilities are poor citizens and unable to care for themselves became concretized in the U.S. social zeitgeist. For example, many people who participated in this research have a perception that society views them as dependent because they do not conform to traditional timelines of leaving the parental home, graduating from school, and securing employment, which are all milestones along a supposedly linear and natural progression of adult independence. I argue that this progression is neither natural nor necessary, but is a key part of the myth of independence in the U.S.

The idea that we all move in and out of dependence through the life course highlights the specious promise of meritocracy. The dogmatic belief in meritocracy—a social system wherein individual success is seen as directly proportional to the amount of work put in (McNamee and Miller 2009: 2)—could be seen as a collective fantasy that a person got to be where they are because they worked hard. This is a decisive factor in one's claim to independence. Consequently, social inequalities are deemed to be fair because meritocracy assumes that everyone has an equal chance of success. In some cases, those who benefit are confident that their success is based only on their hard work and often don't recognize that their privilege afforded them more opportunities and resources than people from underrepresented groups. Despite these realities, the promises of meritocracy mask the harm it creates; it is, thus, a mirage for the middle class and an illustration of the modern American caste system (Markovits 2019; Wilkerson 2020).

"THE PERFECT LITTLE BLIND GIRL"

Among people with disabilities, independence is deeply personal, sometimes fraught, sometimes desired, often toxic and scary. Views surrounding this concept shape behavior and inform decision-making. One mark of true independence within the National Federation of the Blind (NFB) is the ability to get to an airport and find your way to your gate without the use of social affordances. In fact, the NFB insists that members work towards doing everything on their own—the airport is just one example of how that philosophy actually plays out. As someone who utilizes social affordances at the airport, I was shocked to learn I wasn't living up to the NFB's standard of independence. In 2020, I participated in both the Colorado state and national NFB conventions as a 2020 Colorado and national scholarship winner. Part of those scholarship experiences included active participation at both conventions as well as pre-convention workshops. I had also attended numerous local NFB meetings that year. Throughout those experiences, I pushed for the option to use social affordances as a form of independence, often leading to lively debates, which I found to be informative and productive.

Mary's ongoing battle with the concept of independence are tied to her time as part of the National Federation of the Blind. The truth is, some people cherish the NFB while others rue that they ever knew about the NFB. I suggest we think of the NFB as being a source of hope and support for some—but their ideology isn't for everyone. When I'd bring up the concept of independence, Mary would make connections to the NFB. When I'd bring up the NFB, she'd make connections to independence. For Mary, they went hand in hand, inseparable from one another. While a member of the NFB, she was made to feel ashamed for asking for help in public spaces because she said that members are supposed to help change social attitudes about blind people by demonstrating complete independence. "I feel like I have to be the perfect little blind girl every time I leave the house" (Interview July 2022). That's a heavy load to carry, one she could only put down behind closed doors. Feeling the pressure of being the perfect little blind girl infected everything she does. The pressure felt like someone was always watching her, just waiting for her to act blind so they could report back to headquarters.

Let's back up to the beginning to see how Mary developed her relationship with independence. Mary attended the Colorado Center for the Blind (CCB), an independence training school for low vision and blind people. The Center is located in Littleton, Colorado and is part of the NFB. In their own words, the CCB is "grounded in the National Federation of the Blind's positive philosophy of blindness" (CCB.org).

At the Center, it was drilled into Mary that she should work towards a kind of independence where she could do everything herself without assistance from anyone for anything. For a long while, she tried to live up to that version of independence, but it was exhausting. Eventually, she walked away from the NFB altogether because she felt that their version of independence was too narrow and didn't represent her values. "My goal is interdependence because that's how the world actually works", she told me (Interview July 2022). Mary explained that interdependence is working together with another human to get things done. She added that interdependence is based in reciprocity, a mutually supportive system, which she distinguishes from dependence, which she says is when one person doesn't reciprocate support. Interdependence, then, is how Mary crips independence.

At the same time, Mary was quick to remind me that she learned invaluable independent living skills while at the CCB. Prior to attending the CCB in her twenties, Mary had very little familial support, and therefore only minimal access to independent living training. Because of the skills she was learning, she was willing to work towards their version of independence.

It was after graduating from the CCB that she became disenchanted with their ideology. She had tried it on for a while, but it didn't fit. Shortly after graduating, she decided to cut ties with the NFB, but the damage was done. For the last ten years or so, Mary has been trying to unlearn messages drilled into her by the NFB. In fact, she has been seeing a psychiatrist because of the toll it has taken on her mental health. Take a second to read that again. Mary has internalized the NFB messaging so deeply that her mental health is affected. She uses the word toxic to describe the NFB idea of independence. "When I don't live up to that perfect little ideal blind girl, I'm a failure".

Independence is a key point of debate amongst the blind. For example, Paulette Foss (2006) found that blind leaders from advocacy groups often narrowly define what it means to be blind, advancing the values and ideas of their particular organizations. Because of their public presence, they have an outsized impact on the broader societal perception of blindness. That is, Foss argues, the sighted public comes to adopt these narrow ideas and comes to view all blind people through that lens. Those blind people who don't fit the image of the idealized independent blind person become the pitiful handicapped. The reality, of course, is that most blind people inhabit neither of these extremes, but their lives are judged against them.

Prominent among these advocacy groups is the NFB. Their first President, Kenneth Jernigan, referred to his particular kind of independence as "second stage", "rebellious independence", "touchy" and "a pain in the neck to himself or herself and others" (Jernigan 1999 103 as cited in Foss 2006). Jernigan is considered to be an independence Evangelist, who didn't tolerate people who had different ideas than him. His discourse helped shape how the public would come to understand what it means to be blind. Foss argues that Jernigan and other advocacy leaders were the definers of the ideal blind type. Consequently, blind people measure themselves against this ideal blind type which is concretized in the minds of the broader society. Throughout this chapter I look at how this blind figure is reflected back at several people who participated in this research, always hanging over them like the sword of Damocles.

PERCEPTION, MEMORY, AND EMBODIMENT

Harriet lost her vision in a car accident at age 14. Most of her vision was lost immediately, but it took her mind time to comprehend that loss. Her mind refused to acknowledge the loss, using memories to see what she heard. She didn't emerge from her coma frantically screaming, like the season finale of E.R.

Harriet is one of a handful of people who chose to participate in the research by composing journal entries on topics of their choice. Here's one entry where Harriet describes how she came to realize that she had lost her vision: "At no point in time did it occur to me that I couldn't see. When I was with it enough to realize I was in a hospital, I thought I could see things. I'd gesture that I wanted to write something down, so they'd hand me a notebook and a pen. In my head, I could see both objects. I'd write down my questions, and I do remember one time asking them why I couldn't see what I was writing. I don't remember if anyone answered me. To get around, once I'd moved beyond just being pushed around in a bed, they'd push me around in a wheelchair. I thought they were doing that, because that's just what they do in the hospital. I could 'see' the people and walls and hallways around me. When I progressed to walking around, they'd hold onto my arm, and I thought they were doing that because it's just what they did in the hospital. I remember going to another hospital to see the eye doctor or to have eye surgery, but no one ever told me I couldn't see anything, and my brain was reconciling everything by creating images for me" (Journal Entry January 2024).

Let me draw your attention to two things. First, Harriet's mind connects visual memories to her present sensorial experiences. The sounds and smells she senses are connected to images that she collected in her memory as a sighted person. As such, she thinks she is seeing the scene before her, so then misinterprets the behavior of hospital staff, mistakenly thinking that her guided assistance was part of hospital protocol. People embody their sensorial experiences. Sensations are embedded into memories because they become associated with specific symbols. These symbols can evoke sensorial memories that are unlocked by specific sensations (Nichter 2008). In Harriet's case, these memories, evoked by the smells and sounds of the hospital, slowed down the process of losing sight. It was as if her brain had to break the news slowly, a kind of self-defense. In my own case, it took about nine months for my vision to go from 20/20 down to counting fingers at three feet with my peripheral vision. Although I lost my vision in a different way than Harriet, I could relate to the experience of going blind in high school, all be it less traumatically and to a lesser degree of vision loss.

Learning how to make life livable with blindness, reimagining a carefully planned future, and processing, even grieving, was exacerbated by incessant bullying by my peers. So, when Harriet told me she was reluctant to learn braille and how to use a cane in high school, I knew why. I knew how it felt. Using a white cane in high school is like wearing a sign that says, "Hey Stigma, I'm over here!"

CREATING HER OWN ACCESS

To navigate that toxic social space, both Harriet and I distanced ourselves from learning braille and cane skills in a desperate attempt to be normal. Even so, Harriet learned the fundamentals of braille. Nowadays, she still uses her limited braille skills, but she said that she does it mainly for the tactile sensation. It's interesting, not functional. It's more like a hobby than a practical skill.

Once screen readers and other assistive technologies became available to the blind, there was a much lower emphasis placed on learning braille. Although blind people who use braille regularly tell me that it's an indispensable tool, it is no longer a necessary skill for blind people to live independently. Because she doesn't use braille every day, reading long documents is slow and frustrating, so Harriet prefers to use digital accessibility tools for most things. Harriet told me that it didn't occur to her to change how she lived after losing her vision, so she went about living her life as she did before the accident. Taking on service work, competing in cross-country, and taking AP courses earned her a prestigious full-ride scholarship to any school in the state.

Harriett earned a BA and then an MA and added a certificate in education as her intellectual curiosity expanded. During her BA and MA, she scanned all of her own readings into accessible format, a repetitive, tedious, and time-consuming task. Most students I interviewed created their own access at some point, so it's worth taking a minute to look at why.

Public universities provide a service that converts course materials into an accessible format. There is typically an Alternative Text Specialist who oversees a team of student workers tasked with making materials accessible for students with approved accommodations. However, the quality and timeliness of this service is uneven, even between students at the same university. I was surprised to learn how often people described a ruinous stew of ineptitude, favoritism, lack of resources, and misuse of existing resources to describe the Disability Services office at their university. At private universities, there may not be an alternate text service at all. So, it's rare when a student doesn't have to participate in their own access needs.

Harriet told me that she likes to try things on her own before asking for help, but creating her own access isn't what she has in mind. When she said she "tries things on her own first", she means to try in the most vigorous sense of the term, to do until done. She has dogged determination, seemingly motivated by frustration. Let me explain what I mean by "motivated by frustration" by contrasting Harriet with my own experiences. I get extremely frustrated learning new technologies or figuring out workarounds to deal with inaccessible digital platforms. There is often a learning curve that takes time and repetition. Until I become fluent in the technology, I have to hang out in digital spaces that are difficult to comprehend. My knowledge is only partial, so the mental map of what I am doing is blotchy and out of focus. Ordinarily, when I'm in digital spaces, I create a mental map of what's on the screen that I use to navigate with my screen reader, but when my mental map is unreadable, I get irritated. This is all to say that I respond very differently to this frustration than Harriet. Whereas I stomp and holler and invent thinly veiled excuses to avoid dealing with these frustrations, Harriet empties her toolkit of ideas until she figures it out. Over time, Harriet and I have talked a lot about digital accessibility, so I know she's worked for months, often in smaller chunks of time, to figure out technology tools. At other times, it only takes her a few hours or days. That's why I characterized her as being motivated by frustration.

Harriet's reasons for doing everything on her own are twofold. She doesn't want people to perceive her as a societal stereotype of a blind person, and, doing everything on her own nurtures her mind's eye. But doing everything on her own is also very exhausting, so she asks for help if she's running short on time or feeling totally overwhelmed. That is an example of how cripping independence includes flexibility to respond to the fluidity of disability.

The other reason she does everything on her own is that she feels the constant internal pressure to prove to herself that she isn't that stereotype. She said that she internalized a lot of these ideas about blind people herself and feels an urgency to actively resist them. Janis Jenkins (2015) describes a similar situation in the context of mental illness and societal stigma. Even when people had subjective improvements in their mental health with the use of medicine, they still feel the object of societal stigma. In Harriet's case, internalized stigma outweighs the ways she lives independently.

Harriet hasn't been trained in assistive technology, so she doesn't consider herself an expert. Screen readers, for computers and phones, are essential assistive technology tools for blind people, especially if they don't know braille. However, learning to use a screen reader is akin to learning a new language. You can't use a mouse and you can't use your eyes. You have to memorize keyboard combinations that allow you to get to areas that usually require a mouse. Yet websites require unique navigation, and new technologies often require learning a totally new set of keyboard combinations, so the learning is continuous. Harriet learned through trial and error as well as through online resources. She is tenacious and has a mind like an engineer, drawing on her past experiences to figure things out. However, she will tell you that it's because she doesn't have a choice. If she wants to live on her own, to do anything online, to live life, she has to be stubbornly patient. She can't just ask for help like I can.

HARRIET'S PLACE

Harriet lives by herself in a three-level condo nestled at the base of the foothills of the Rocky Mountains. To find her home, I followed her instructions, which directed me to walk through the middle of a tree lined park, over a brook, and up to the back of her condo. Once I crossed the brook, I found myself walking through a narrow strip of grass, surrounded by a wooded area, the air heavy with the perfume of summer blossoms. I called Harriet on the phone, and she guided me to her gate where her service dog greeted me. It was the first of several occasions when Harriet generously welcomed me into her home to show me how she lives independently. I present this narrative to demonstrate how Harriet crips independent living.

All of Harriet's furniture is arranged along walls, keeping the central areas free of obstacles. I wouldn't have to worry about my shins. While she was showing me around, she told me that she prefers to use a vacuum to clean the floors because she's more confident in the results. She can just keep vacuuming the same spot until she doesn't hear anything getting sucked up. Sweeping is a bit trickier. She can't tell where the piles are or if she's even created a pile or if she just rearranged the dirt.

Our plan on my first visit was to bake a loaf of bread, have some coffee, and talk about what it means to live independently. I asked Harriet how she knows what she is grabbing from the pantry. She said that she can narrow it down by the texture, weight, and sound a container makes. Often, she'll smell and touch open containers. For sealed containers, she typically uses a digital app she calls her Pen Friend, or an app called Seeing A.I. Unfortunately, these apps aren't immune from glitches and quirky behavior. On this day, she couldn't find her Pen Friend and Seeing A.I. took a sick day. She spent about ten minutes troubleshooting until she decided to show me how to see using my hands, a seamless transition from digital to analog.

She could tell salt from flour by the shape of their containers but didn't measure the ingredients with measuring spoons or cups. She cupped her hands to measure the dry ingredients. Slowly, she cupped a few ounces of water at a time into the dry mixture. Using only her hands, she stopped adding water once the dough reached the proper consistency. Using cooking gadgets removes the tactile experience, so she prefers to use her hands. The bread had to proof, so she sent it home with me to enjoy with my family. We got a bit more ambitious for our next meal.

When I got to Harriet's house the second time, we sat at her breakfast nook with coffee and the occasional sound of a hummingbird streaking by her window. She's part of a farming co-op that delivers seasonal produce to her each week. The produce is always a surprise as farmers send what's ripe. In this basket, we knew we had an onion and were pretty sure we had summer squash and zucchini. She was right about the summer squash, but the zucchini was a cucumber. When there are similar unknown veggies, she just tastes a piece to know for sure. If it's the wrong item, she just saves it for the next meal.

Once she figured out the vegetables, she went about chopping onion and squash for our omelets. She tossed the veggies into an air fryer, a tool that makes cooking much easier for her. It's safer, cleaner, quicker, and the food is cooked to her liking each time. She moved on the prepping the eggs, which she did by gently cracking them and then prying them open. Sometimes she gets a bit of eggshell in the eggs, but she's used to the occasional crunch. "It adds texture", she said with the toothy smile that made me wonder if she was fucking with me again. Harriet is hilarious and we tend to laugh a lot, at ourselves, at the sighted world, and the coded jokes decipherable to the blind but unknowable to the sighted.

She finished the first omelet and asked me to hand her a plate. The plate had a few raw eggs on it, so I was confused when I realized she was going to put the cooked omelet on the raw eggs. Then I realized, this must be some kind of cooking hack she's figured out, so I asked her how long it would take for the omelet to cook the raw eggs. She looked at me incredulously, completely flabbergasted. She wanted an empty plate. There was no cool blind trick after all, just a classic example of the tiny, often funny, moments in the day of the blind. We ate and headed outside for a bit of gardening.

Harriet's condo building was one of many similar buildings along the edge of a wooded area behind the park I walked through to get to her condo. Harriet planted her garden where the grass gave way to nature. The skeleton of a raised bed sat partially buried. Weeds were everywhere, crawling along the dirt, climbing up thicker stalks and rising out from the bedlam. But Harriet doesn't see a bed of weeds, she sees rows of vegetables, some offering a constant bounty, and some unwilling to offer their fruit. She smells the leaves and flowers of the plants and touches them to feel their shape, size, and texture. She leaves the weeds until the plants produce fruit. Then, she plucks the fruit and pulls the weeds. Waiting to pull weeds stops her from weeding her immature vegetables. Outside of the garden bed, she'd planted a few bushes amongst the tall grasses and endemic flora.

Harriet stepped outside of the raised bed and into the wooded area with me on her heels. She showed me a cherry tree, then a plum tree, and after running her fingers along the branches of natural bushes, she found her gooseberry bush, a highlight of the tour. She showed me other things she had planted haphazardly around the woods in the same way the native plants arrange themselves.

Harriet lives independently by using technology and rearranging existing relationships to form new attachments (Moser 2006). As a sighted person, she had formed an attachment to her vision, as sighted humans do, to make life livable. Now, she's formed attachments with her other senses. Further, Harriet has formed new attachments with a service dog, white cane, and assistive technology, which have become catalysts to independence, making legible a sighted world.

I hope that sighted readers slow down here to reflect on the notion that it might just be possible to know the beauty of the world, even for blind people. Let it stick to your ribs. Now, I realize that discourses of independence in the U.S. includes the ability to be self-sustaining, so I focus on Harriet's job in the next section.

"DISCRIMINATION OF THE SUBTLE VARIETY"

One reason Harriet can't work full-time hours is because in order to keep SSDI benefits, she can't exceed a small monthly income. The government defines disability by a person's ability to work, a measure of economic value, not of human value. Consequently, SSDI is not intended to make people thrive, just to stay alive. A person can cobble together a life with SSDI and part-time work, but the system prevents them from thriving.

Another important reason why Harriet works part-time is because of a mental illness. Taking a page from Audra Simpson (2007, 2014), I refuse to describe the specifics of Harriet's mental illness. I include its existence only to point out an important reason why she can't work full-time and because it's a complicating factor in her work experience. It is episodic in its intensity, requires medical appointments, and there are periods of time when she can't work, so the flexibility of a part-time work schedule is crucial. However, the need to keep that flexibility has hamstrung her ability to get promoted.

Harriett's boss says that she can't take on any more responsibilities unless she is willing to work more than twenty hours. "He won't let me bring up disability, so I'm not allowed to explain my SSDI conundrum to him" (Interview July 2022). Harriet wants to explain that the reason she can't work more than 20 hours per week is that she needs to keep her SSDI benefits.

However, he blocks her from having that conversation with him, saying they're not allowed to discuss disability in the workplace.

Since the Covid-19 pandemic, she has felt like she's been singled out even more. During the pandemic, everyone at her office lost weekly work hours, but when other employees got their hours back, Harriet had to prove why she needed the hours back. She had to write several justifications explaining she could take on the work, even though it was the same work she was doing before the pandemic. She calls it discrimination of the subtle variety. The kind you find yourself accepting as it envelopes you. She's scared to leave her job though because it's really daunting trying to find a job as a blind woman. Discrimination in the workplace is a common experience among people who participated in my research, and Harriet's workplace experiences are not unique among people with disabilities. Deborah Carr and Eun Ha Namkung (2021) found that workers with disabilities report higher rates of perceived discrimination and lower levels of supervisor support.

Despite the ADA and the increasing adoption of Diversity, Equity, and Inclusion programs, the hiring process remains a major barrier to employment for people with disabilities. There is a lot of strategy involved in deciding when or if to disclose a disability to a potential employer. Employers have learned how to get around hiring protections. For example, a potential employer cancelled an interview with Harriet when he found out about her blindness and that she uses a service dog. The employer told her they'd have to cancel the interview because the company was in the middle of relocating. He never called her back. Job interviews are tricky terrain to navigate for people with disabilities. According to a Vocational Rehabilitation Counselor I interviewed for this research, the hiring process is so important for people with disabilities that it's often included as part of disability advocacy groups' training curricula and that of governmental organizations, such as the Division of Vocational Rehabilitation (Interview July 2022).

Harriet requires SSDI to maintain her independence. It is the paradox of the disabled. Many people told me that they require dependency to be independent. Whether it is an interdependent relationship, assistive technology, or governmental assistance, losing those supports takes away the ability of people with disabilities to be independent.

DECISION MAKING

Despite all of the ways that Harriet lives life independently, the idea of dependence remains part of her decision-making process. The best way to illustrate this is with her own words. Below is part of a diary entry that Harriet generously shared with me. My analysis follows.

> I've decided to apply for Access-a-Ride. I've been riding the bus for 22 years, so it is an odd time for me to apply... I guess part of what has stopped me from applying is the fact that I'm proud and independent, and I want to say that I can ride the bus just fine. In applying for Access-a-Ride, I need to say that I can't ride fixed bus routes some or all of the time. I'm going to claim that I can't ride fixed bus routes some of the time, because I can't find my way to and from bus stops and my destination when I'm in unfamiliar places. Technically, this is true, and strictly speaking, it's not true. Sure, there have been more than a few situations in which I'm wandering around forever, trying to find my darn destination or a bus stop. I can't see them. However, there are also techniques and resources to help me find places. Google Maps is one big one; when it's in walk mode, it generally tells me I've found my destination when I'm right in front of it. It does then take some finding to get to the front door, but there are things I can do to try and find that. Another big resource is the random people standing around places. I'm not afraid to ask for help finding a place. But then technically, I'm not finding it on my own. So, I go back to claiming that I can't find places on my own. Or at least I feel like I'm not totally and completely lying when I say that I can't completely find places/bus stops on my own. Oh yeah, also there are times when construction gets in the way and very much makes that true. Not to mention times when there isn't a light or a sidewalk... there really are times when I can't use fixed bus routes. I'm not ashamed of what I'm doing, but I'm also not super proud. I guess I'm just emphasizing different parts of my disability than what I really want to emphasize. But if that's what I have to do for the system to give me what I should have access to... I guess I'll do it.

The decision for Harriet to apply for Access-a-ride means that she has to change her sense of self. She worries about how people will perceive her and feels like she is losing a sense of independence, a source of pride. Even though she's been riding buses for 22 years, she has to claim that she can't ride fixed bus routes, at least some of the time. To make that claim, she has to emphasize certain aspects of her disability. To apply, she has to lie. To put the magnitude of this decision in perspective, consider that it took her more than two decades to apply. My argument is that part of her past dogs her today. That is, her attitudes and values are part of her identity, her sense of self, so when they change, it is a slow process. The past isn't a light switch you can flick off. For Harriet, being perceived as dependent arouses all kinds of memories that cause her to feel as if she's got to prove her independence.

In writing Harriet's narrative, I have tried to describe how she lives independently without romanticizing her life. It should not be awe inspiring to learn how someone lives with a disability. Celebrating ordinary tasks as remarkable accomplishments is infantilizing and rooted in ableist attitudes. Moreover, it implies that a person has had to overcome or transcend their disability to complete a given task. Harriet's story is intended to show you how people make life livable, even if differently.

HANNAH'S STORY

I met Hannah the summer before her last year of her bachelor's degree. We were just getting to know each other, and I was asking questions about what she likes to do for fun. She has a very active social life and does a lot of outdoor activities, like running, biking, and rock-climbing. She wants to learn to roller blade, but she has to wait until her hip heals. While walking through a building on campus, she slipped and fell on her hip because the wet floor sign was blocked by a group of people. Later that day, she fell off of her bike, aggravating the same bruised hip. Don't worry, she was okay, just a bit frustrated that she wouldn't be as active as usual for a week or two.

Hannah identifies as visually impaired, meeting the threshold to qualify as legally blind, and has recently been diagnosed with ADHD. As I write, she's entering her second semester of her MA in Education. One of the first things I learned about Hannah was her expertise in public transportation. She learned these skills through Orientation and Mobility training she received throughout her K-12 education. Orientation and Mobility specialists teach independent living skills to blind people, such as travel, braille, and other important independent daily living skills. Before the ubiquity of accessible phone map and travel apps, blind people used address interpretation more frequently, but it remains a crucial skill. Hannah told me that in the U.S. most cities use the same street design where named streets are intersected with numbered streets. Even numbered addresses are on east or south side of streets, and odd numbers are on the north and west sides. If she knows the address where she is, she can figure out how to get to where she wants to go. She learned how to cross streets by listening to the sounds of cars. If the cars to her left are moving, she too can move. If there are cars noisily approaching or quietly fading in the lanes in front of her, she knows not to cross. It's a skill that takes time to develop with confidence. In other words, there is a chasm between knowing how to cross the street, especially with a trusted trainer by your side, and putting those skills to the test. When you're blind, you can't peek, there's no cheating.

To navigate with sound, you listen to the choir of throaty and lightly purring engines and wheels whizzing by. They are mere textural soundscapes for the sighted, but to the blind, they create a map. Those sounds show blind people where vehicles are located, if they are idle or moving, how fast they are moving, and most importantly, if they are going to intersect your path. People hollering, horns honking, shrill sirens of emergency vehicles, backfiring cars, and booming music are a small sample of the audio chaos that can hinder a safe traffic crossing. Each of these sounds affect the clarity of the map you created, as if Jackson Pollock throws a glob of paint with each sound, splattering across your map.

A lot of blind people use this skill in combination with audible traffic signals, a highly contentious topic amongst blind people. The National Federation of the Blind advocates against audible traffic signals because they feel that they could lose the skills they've honed to navigate independently. I couldn't figure out how audible traffic signals would dull their travel skills, and nobody has been able to explain it to me in a way that makes sense to me, which is likely a reflection of my personal bias towards using audible traffic signals.

There's also a perception among some NFB members that the technology is not trustworthy. "There's been a bunch of times when the sound thing didn't work at the right time and a blind person got hit by a car", as someone noted at the NFB Boulder chapter meeting in April 2020. Certainly, the technology malfunctions from time to time, but the discourse that audio traffic signals malfunction is circulated among members and is taken up as imminent. Listening to Hannah as we walked around crossing streets, it was clear that she uses a combination of those independence skills alongside audio traffic signals when available. She is an expert in blind navigation.

Before your inspiration radar goes off, I ask you to resist that urge. Don't scratch that itch. I'm not speaking for Hannah here. Sighted people are surprised when they learn that she is so active, which for Hannah, is grating. "I hate it when people say I do so much even though I'm blind" (Interview July 2022). It's so grating because it's not a recognition of a cunning mind or peculiar talent, not a recognition of equality or acceptance, it's a celebration of overcoming disability.

People simply can't square their beliefs about disabled people with the real lives of disabled people. They assume that a person has overcome disability if they participate in public life. The phrase, "even though I'm blind", from Hannah's quote above, vanishes the veneer of authenticity because it suggests disability is a state of incompetence. As Erving Goffman (1963: 15) puts it, "His once most ordinary deeds—walking nonchalantly up the street, locating the peas on his plate, lighting a cigarette—are no longer ordinary. He becomes an unusual person. If he performs them with finesse and assurance, they excite the same kind of wonderment inspired by a magician who pulls rabbits out of hats". Finding it remarkable that disabled people can do ordinary activities that you do with ease means that you don't think disabled people can do things on their own, that they are reluctant recluses, typically dislocated from the public sphere. You find it mind-boggling that a disabled person is independently going about their day, daring to be normal.

It can be felt as biting, a venomous sting. It's a common sentiment that unleashes a burst of ableist fallacies that can dehumanize people with disabilities by erasing their independence. Let me give you a frequent example from the pages of my journal.

I used to live about a ten-minute walk from a small store in a liberal town. I went there all the time, often to grab random supper ingredients on my way home from work. They also had a great bakery that might have beckoned from time to time. Anyway, there's a checker who works there who gives me a hug each time I come through his line. I tried to avoid his line, but I can't see well enough to know which line to avoid. It's a small store with only a few lines, so I usually wound up in his line. Sometimes, he spots me trying to avoid his line which he misinterprets as me helplessly, desperately, urgently waiting for someone to help me. He swoops in for the rescue and scoots me into his line.

As he scans my items, he showers me with all kinds of compliments about how amazing it is that I'm out and shopping all alone. He even thinks he sees me walking around town sometimes. I'm a real inspiration. Once he finishes explaining which items he's bagged together, he comes around the register to give me my hug, so kissably close that I always feel his white stubble and smell his juicy fruit breath that doesn't mask his oncoming gingivitis. There I am, a PhD student getting a hug, like a good puppy, for all to see. Hannah and I aren't alone in these infantilizing experiences that index societal stigma about disability. Of course, there are important exceptions, especially for people who are recently disabled, for whom this discourse can sometimes be a source of respair. Those are deeply powerful experiences that I want to acknowledge. In my research, though, this was the exception.

NONVERBAL SOCIAL CUES

Sometimes, when talking to another blind person, like Hannah, I'm able to perceive my own experiences in a new way. That's what happened when Hannah started to tell me that she's not aware of her own facial expressions at times. Someone once told her, for instance, that she squints when in conversation. Likewise, she isn't aware of certain common facial expressions until she reads about them, for example, when she reads a book and a character quizzically raises one eyebrow. You can't know what you can't sense. Maurice Merleau-Ponty (1922), in describing the sensation of touch, explains that you can't apprehend the existence of something unless you first experience it. The thing doesn't exist until it is known through sensorial experience. Hannah can't see other people squint when they talk, so she has no way to know that it is a common enough facial expression with the same communicative power as the spoken word. Its meaning is relational to the social context.

As Hannah told me her story, I thought about the times I forget to aim my eyes at people's faces, especially when I first meet someone, and they don't know I'm blind. You see, I have no central vision at all. If you're standing five or so feet away from me and I aim my eyes at your face, you look like you've been beheaded, and your head has been replaced by a fiery globe of bright colors. Beyond your head, I can see the scene, with varying degrees of clarity. If you imagine a circle split into quadrants, the lower right part of my right eye has my most acute vision. Over the years, I've strengthened the natural instinct to use that part of my vision, and therefore aim my eyes up and to the left if I'm looking at someone or something. To you, it appears that I'm staring at a point beyond your right shoulder. When I talk, which I do a lot, it looks to you like I'm talking to someone past you, yet I'm responding to you. People who don't know me often turn their heads to see who the hell has attracted my attention, a truly confounded expression on their face. Some brave people even ask me what I'm looking at. Both responses are deeply embarrassing, a wound I wonder if they wanted to cause. I understand that most people who respond to my awkward gaze don't intend to hurt me. Even good people react instinctually. It's still embarrassing.

Getting back to Hannah, she told me that it is difficult for her to read facial expressions and she misses a lot of social cues. We know that people use their bodies differently across societies, what Marcel Mauss (1968) calls "techniques of the body". We also know that people generally know how to use their bodies within their own sociocultural context. Even within societies, techniques of the body change over time as new knowledge is incorporated, as in Mauss' example of swimming techniques. In addition, habits of the body are peculiar from society to society, including the way that people walk, greet people, how they sit, their mannerisms, in general, all the unconscious ways of moving the body that are learned as a person unconsciously soaks up their social worlds (ibid.). It has been interesting to think about how blind people navigate professional spaces where reading social cues is part of the job, so I'll turn to one of Mary's stories to help me think about this.

I knew Mary as an undergraduate student, as a graduate student, and now, as a professional. She now works as a therapist leading group therapy sessions consisting of people with various mood and anxiety disorders. When I asked her how she navigates the visual aspects of therapy, like reading the faces and body language of her patients, she said she listens for tone of voice and tries to pick up on the energy of people and group dynamics. It's a process that can take time, but she concentrates on building rapport, so people feel safe talking to her. She also asks a lot of questions. For instance, if she enters a group and senses tension, she will ask, "Hey, I feel a lot of tension here, what's going on"? Although she misses head nods and eye rolling and things like that, she can typically hear body language. She said that emotions can change the tone and texture of a person's voice. It's just that sighted people need nonverbal visual gestures to make sure what they are hearing from a person is accurate. Admittedly, she misses nonverbal gestures that aren't accompanied by a corresponding audible sound. Similarly, she said that when someone is covering their mouth or facing away, there is a change in their tone. Being attuned to her patient's nonverbal gestures, Mary is able to connect with her clients in a deeper way because she is focused on developing rapport.

I've taken you on this brief detour from Hannah's narrative to demonstrate how Mary uses her non-visual senses to aid her in reading social cues, which is a creative use of disability expertise.

SHEDDING SOCIETAL SKIN

In this section, Hannah generously invites us into her private thoughts to witness her go through the process of accepting blindness and ADHD as part of her identity. I argue that claiming independence on her own terms is how Hannah crips independence. Hannah grapples with the idea of not thinking about compensating for her blindness but it is hard to get past feeling inferior. Despite the societal structures that litter her path with ableism, Hannah has productively struggled through this inner tension.

Hannah's positive relationship to blindness is recent and was the result of numerous factors. For most of her life, she was always worrying about presenting herself as blind. It was a constant source of anxiety that boiled over. She would introduce blindness but quickly, urgently, explain all of the ways she could make up for it. She learned that she wasn't living her life just to prove to others that she can do x, y, or z. Asking for help isn't weakness. She had to convince herself that when friends help her, it is not a burden to them. She learned to trust and accept love from those she trusts. She grew up thinking that she couldn't depend on another person. If she had to get assistance from others to survive, that was a bad thing.

In high school, Hannah was trying to figure out how to fit in socially as a person with a disability, but she wasn't presenting her authentic self. Her orientation and mobility teacher, who had known her since kindergarten, told her that she really cares for Hannah and that the person she saw Hannah presenting to her peers wasn't the person she knows. Her teacher feared Hannah would lose herself as she negotiated social situations. Part of what Hannah's teacher observed was Hannah's attempts to compensate for her own internalized stigma.

Now, she feels independence is knowing how to use and trust the people around you to navigate your world. It is learning how to trust and to accept help. Interdependence is a symbiotic relationship where you rely on a network of people who in turn rely on you. She learned that she probably could do everything on her own, but she would end up really exhausted, lonely, and miserable. She began to embrace help from family and friends. In the past, she'd hesitate to ask. Nowadays, her close friends and family alert her to obstacles and other hazards when in public. She's also more comfortable asking to be guided when things get dicey. They are subtle, never drawing attention to her, just another part of the crowd.

Hannah's work experience provides a lens that illuminates her evolving sense of self, and therefore, her ideas of independence. In short, she was perceived to have a deficit by several employers and managers, so she felt like she had to prove that she could compensate for her blindness. As I will show, however, Hannah has changed from feeling like she is a problem to identifying as a person who is visually impaired and can do just about everything that everyone else can do, even if differently. She has come to embrace interdependence. In this section, I trace Hannah's evolving relationship to her disabilities with ethnographic vignettes from work, school, and her social life.

During one job interview at a coffee shop, the interviewer was hesitant to hire someone with low vision. Unlike other applicants, Hannah had to prove she could run the register as part of her interview. Hannah obliged and demonstrated that she could operate the register. Even so, it was for nought. She was told they couldn't hire her because they couldn't look over her shoulder to make sure she didn't accidentally shortchange customers. Hannah explained to me that these kinds of experiences made her feel like she was a problem, and it motivated her to prove people wrong about her. As she accounted to me, in the past, Hannah felt she had to prove why her blindness wouldn't be a problem, that she could perform any task asked of her, that she could compensate for her blindness. It was frustrating and exhausting.

Hannah was hired at a King Soopers grocery store as a checker. She was trained on the register at first, but before she had a chance to work in this capacity, her manager abruptly demoted her to a Courtesy Clerk. Hannah's manager, moreover, even told her that she was demoted from the registers because of her blindness. Working at the register paid more, was more interesting, was in line with her skills, and is a safer job than her new position as a Courtesy Clerk. In this role, Hannah's job responsibilities included: bagging groceries, navigating the public and warehouse spaces of the store to do various tasks, helping customers with their groceries, and collecting carts from the parking lot and pushing them to the designated pockets in front of and just inside of the store. It's not that she can't do these tasks—the problem was that many of these tasks can be dangerous for people with vision disabilities. When her manager found her collecting empty carts in the heat and said that nobody else would work in that heat, he wasn't concerned that a blind employee was collecting carts in the parking lot, he was implying that she was tougher than other courtesy clerks for working in the hot sun. She told him that she felt like she had to prove she could do it. Otherwise, she told him, he wouldn't take her seriously. Risking her own safety, she was intent on performing the capacities of a sighted employee.

While Hannah was busy proving herself as a Courtesy Clerk, she befriended another checker who secretly trained her on the register. She was determined to show her manager that she could operate the register so that she could get her job back as a checker. Eventually, her tenacity paid off and they let her work the registers. The register debacle made her feel like she had to compensate for her vision. Hannah only began to change how she felt about her vision after leaving the service industry and successfully applying for an internship at a local museum.

Hannah had applied to a "diversity in the arts" program she learned about in college. The museum hired her knowing she was part of a marginalized group, so she wouldn't have to worry about her vision as a deficit. Finally, she was able to just focus on the work. In fact, she feels like her blindness was an asset for the museum because she brought knowledge of disability and ideas of how to create more accessible exhibits. She told me that her mere presence made people think more carefully about accessibility when they created exhibits. The staff had thought ahead to try to proactively create accommodations for her and were flexible as she requested emerging needs. Inclusivity and diversity enrich museum exhibits by making them accessible to broader audiences. Hannah's experience as an intern at the museum was a catalyst in her shifting ideas of disability.

"REACHING FOR THE STARS BUT ONLY CATCHING DUST"

When Hannah was in her final semester of her undergraduate degree, feelings of pride and excitement were often crowded out by simmering anxiety about life after graduation.[1] Soon, she would lose university resources and be totally self-reliant. Naturally, then, independence was on her mind even more than usual. In April of that semester, she reached out to me and wanted to talk. She was upset and overwhelmed because she suddenly had to drop out of her undergraduate thesis program. She explained that she had source access issues. I would come to learn that the reason was actually because of discrimination. Hannah hadn't yet dealt with access issues that she couldn't resolve on her own, and so was shaken by the situation.

The problems began when she submitted her first draft to her committee. She felt their feedback was unreasonable, saying she needed new research questions and more primary

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[1] Heading from Drive By Truckers. 2022. Shake and Pine. Welcome 2 Club XIII. LP. David Barbe.

sources, including a list of the specific primary sources they wanted her to use. She had two weeks to address their critiques. She knew it would be impossible to do because she couldn't check the sources out from the library; they are part of a collection of primary sources. Not only would she have to travel to a different city for these sources, but they are inaccessible to her in their paper format. She would need to have them scanned into digital format to access them, and that was out of the question. When she reminded her committee of her blindness, they told her to take photos of the pages she would need and then just O.C.R. them (in other words, use Optical Character Recognition technology). Hannah said that this showed that they didn't understand the complexity of vision loss and made the common assumption that the change itself from paper to digital would resolve her access issues. She felt like they minimized her blindness and dismissed it as none of their concern. She told them that their idea wouldn't work and that she didn't know how she could make the primary sources accessible if she couldn't take them with her. Still, they offered no flexibility. They offered no support and no extensions. They effectively terminated her thesis, something she had worked towards for a long time. To salvage her grade and graduate on time, she withdrew from the thesis. After weeks of intense negotiation with her committee, she was able to figure out how to pass the course and graduate on time.

Even though we had talked previously about how she felt about independence, Hannah emphasized several times that she wanted to graduate with that honor to prove she could do it even with ADHD and blindness. She said she was used to doing things on her own in school, developing workarounds when she encountered a barrier. But, during her thesis, she ran into issues she couldn't do on her own for the first time and was unprepared to address them. As a result, she felt like a failure when she couldn't figure out how to get around this barrier. She said that it's difficult to prepare for something if you don't know what that thing is you need to prepare for. She had always tried to live up to societal expectations of independence and never accept assistance, but she reflected that it caught up with her this time, placing some of the blame for this situation on herself.

Hannah has had to come to terms with a lot as a result of this experience and it was a mentally and emotionally exhausting period of time. She talked a lot about how much time it takes for her to do things and it felt like the burden of accessibility was clearly on her and she became too exhausted to keep fighting. Even though she never got things fixed, she spent a lot of time in meetings and writing emails trying to survive the situation. I've been focused on independence as I write about Hannah, but you should be able to locate crip time and assess its consequences in Hannah's story as well.

Hannah's thesis experience was revelatory because it was the moment where she realized that the independence she had been seeking is impossible. Simultaneously, and perhaps most crucially, she realized that nobody, disabled or not, can truly live that idealized version of independence. Hannah realized that she wouldn't be able to do everything on her own after all, especially once she completes her degree. Her positive experience at the museum where she began to shift from always trying to prove herself despite her blindness to embracing a positive relationship with blindness, was foundational to Hannah embracing independence on her own terms and, thereby, cripping independence.

As I shift to a recent experience I had in graduate school, I want you to keep Hannah's story in mind. In the following story, you will see just one example of the ways that my academic advisor and home department have supported me when I've faced disability related barriers. It demonstrates my version of independence, a version only possible through interdependent relationships. Collectively, my support also highlights an extraordinary amount of privilege. I, therefore, feel a responsibility to advocate for disabled students who have no support. I've chosen to juxtapose Hannah's experience against my own to highlight our contrasting experiences. Another important point is that independence is a highly contingent concept for both Hannah and me. Independence isn't fixed once achieved; it relies on sociotechnical relationships of interdependence that facilitate independence. Cripping independence is, thus, an ongoing process.

BRITTLE PRIDE

Applying for a major research grant to fund dissertation fieldwork is an important part of the PhD process. It's not just a hazing ritual. It also does much more than fund dissertations, it can launch academic careers. An unsuccessful application, on the other hand, can delay progress to graduation, limit career opportunities, and even end the PhD journey. To say that the stakes are high is an understatement.

I chose to apply to the National Science Foundation (NSF), which would require me to work with the Office of Contracts and Grants (OCG) on my campus. The process requires me to fill out forms that are approved by a contact person at the OCG because the NSF is apparently cranky about formatting. To my horror, the forms were inaccessible. Trying not to panic, I reached out to my doctoral advisor for help. She, in turn, reached out to my contact at the OCG to explain that I would be applying for an NSF grant and that I may have some accessibility barriers.

In response, my contact person told me she didn't know how to create accessible forms and directed me to the Digital Accessibility Office (DAO). The message was clear: it was not the responsibility of the Office of Contracts and Grants and, therefore, not her problem. To her delight, I explained that I work for DAO, but to her chagrin, I told her DAO offers consultations and training for digital accessibility, but it is the responsibility of the OCG to make their documents accessible.

I reached out to Disability Services to see if they would be able to help me. Perhaps they could turn the forms into an accessible format. I had been hesitant to do so because NSF deadlines were fast approaching, and it can take several days at a minimum to send me accessible materials. DS prioritizes student accessible format requests in the order they receive them. DS responded:

“I can try to work with the forms. Unfortunately, forms are a real pain in the butt unless the person creating them did them in an accessible way. HTML forms are usually pretty good; anything else – PDF, Word – are not. The first thing I would recommend is that you push back very, very hard with the entities that are throwing up roadblocks. Threaten them by getting the NFB involved. As for the on-campus office you are working with, shame on them. THEY need to be taking up their accessibility, just like every other department on campus. They need to work with the DAO on their own forms and processes, to make them accessible. They don’t get a pass on this”.

This email shows empathy, demonstrates care, and although well-intended, these solutions all required more work, and thus, more time. Likewise, threatening and shaming people doesn’t help, it alienates the people who you need to help you. In short, DS didn’t have a good solution for me either.

With the application deadline approaching, my advisor hired another graduate student to work with me. I could have insisted on waiting for the forms to be fixed so that I could fill them out by myself, but it could take months to make that possible. If I insisted on doing everything myself, the reality was that I would have to wait until the next NSF application cycle. Despite the humiliation I felt, I chose to save time rather than insist on doing the application totally independently.

Flaunting my naivety, I thought that since I now had sighted assistance, my troubles were behind me, and I could just devote my attention back to the actual content of the application. I told the Office of Contracts and Grants that I had help so not to worry about accessibility for now. So, I was a bit peeved when they started trying to make the budget justification document accessible using different colored font, which my screen reader does not perceive. Since they were making the effort, I felt obligated to keep reviewing the documents. Once again, I found myself protecting the feelings of people who were making my life more difficult. Finally, I explained to my contact that she was just creating more work for me. I had spent two days conducting an accessibility review and training instead of working on my NSF, my dependencies amplified, threatening to define my narrative. No matter my successes, the fear that I could be perceived as dependent continues to haunt my life. I fear that the perception that people form about me won't align with how I perceive myself.

CONCLUSION

Sonya has a full-time job as an advocate for blind or partially sighted people. She is blind and uses a guide dog. You'll get to know her more in the next chapter, but I want to introduce her here to show you how her use of a guide dog facilitates independence.

Sonya's guide dog helps her to travel and work independently, but she finds that a lot of people try to strike up a conversation with her because they are curious about her guide dog. She has found that she can still educate people she encounters in public spaces without letting them pet her guide dog. She usually treats these moments as if she's a blind ambassador to the sighted world. "People need to know that blindness is not a death sentence. I think the common perception of the public is when you're blind, there is nothing left for you out of life. I think people don't have a concept of what it would be like to be blind because we are a visual society… But I mean, there are blind people living and functioning in the world, so we are living proof that you can do it. You just have to acquire the skills and techniques and be open to adapting to live in a different way and engaging with the world in a different way. I just wish sighted people knew that there was more to blindness than just the lack of sight" (Interview October 2022). Sonya expresses a common sentiment among people with disabilities in this research, the desire to shatter societal ideas about disabled people. For Sonya, a guide dog is one way of changing those stereotypes. She is reframing blindness as another part of human diversity and moving the conversation away from the idea that blindness is a deficit.

Although there is constant pressure to make visible independence in public spaces, Mary, Harriet, Hannah, Sonya, and I all live independently and crip the subject position of the independent neoliberal citizen in our various creative responses to disability and its social impacts. I've developed the concept of cripping independence as a conceptual framework that takes seriously the unique ways that people shape independence to their own circumstances. Ultimately, the stories in this chapter highlight the ways five people with vision impairments grapple with how their decisions will affect perceptions of them, as well as the various ways that they live independently.

CHAPTER IV

THE COGNITIVE LOAD OF LIVING WITH DISABILITIES

In graduate school there is an expectation that students will simultaneously publish articles, present their work at professional conferences, teach, and conduct research for and write their dissertation. It's a heavy load unevenly balanced across those competing demands. But there is an additional load for academics with disabilities. Brittany and Sonya, two research participants, independently characterized their disability-related stress as a cognitive load. The purpose of this chapter is to develop that concept into an academic framework generalizable to disability worlds (Ginsburg and Rapp 2013, 2024). Cognitive load is the brain power it takes for a disabled person to navigate social, educational, and workplace spaces. Disabled faculty and graduate students bear an inordinate cognitive load invisible to people outside of disability worlds. The cognitive load that comes with living with a disability is omnipresent, yet its intensity emerges from the social context. That is, the cognitive load specific to disability is fluid, always present but made worse by ableism, making it intractable at times.

In her book *Crip Spacetime* (2024), Margaret Price explains why policies intended to improve access and inclusivity in academia actually increase inequity. In doing so, she develops the theory of crip spacetime. "Crip spacetime as a theory attempts to explain what it means to be disabled as an academic at this historical moment" (Price 2024: 5). Price is an academic with disabilities who is problematizing the idea of individual accommodations, specifically focused on the experiences of academics. I engage with her work throughout this chapter. Price begins her book by listing the litany of possibilities and preparations that a disabled person must calculate in nearly all aspects of their lives. It is precisely this litany that creates, stores, and adds to the cognitive load borne by people with disabilities.

When people who haven't experienced disability make uninformed assumptions about people with disabilities, it is often because they haven't accounted for cognitive load. In the educational environment, three common assumptions that emerged in my research are: If you can't drive, just take the bus or ride share; using assistive technology means you can access anything in the digital environment; and academic and workplace accommodations create total equality. While dispelling those fallacies, this chapter shows what is at stake for people with disabilities when they encounter those assumptions. Here, I will discuss how they increase the burden of a person's cognitive load.

Everyone, disabled or not, carries around a cognitive load. It is more apparent in disability worlds because people with disabilities also have to carry the cognitive load related to their disabilities. The cognitive load of disability worlds can only be known through living with disability or caring for someone with a disability. If you're not part of those worlds, I'll do my best to bring you close. I build on the theory of structural vulnerability throughout this chapter to explain why only those living in proximity to disability can truly understand cognitive load. I then locate its cause and explain how it impacts employment and educational experiences—and even more crucially, how it impacts mental and emotional well-being. Structural vulnerability can be defined as, "a positionality that imposes physical/emotional suffering on specific population groups and individuals in patterned ways, [which is] a product of class-based economic exploitation and cultural, gender/sexual, and racialized discrimination, as well as complementary processes of depreciated subjectivity formation" (Quesada et al 2011: 340). I add disability and ableism to this definition. The cognitive load borne by people with disabilities can cause mental and emotional distress, which results from their vulnerable positionality within institutional structures and hierarchical sociopolitical power relations. Discrimination connected to disability is systematic because it can be relieved, but ableism blocks that relief. Moreover, there is a pervasive ordinariness people with disabilities come to know about their positionality within the social hierarchy. Despite its ordinariness, it's situationally dependent and is highly subjective. Finally, people who don't typically experience discrimination tend to think that "-isms", like racism and ableism, are easily spotted, always obvious and through a binary lens of yes or no. Oftentimes, discrimination is subtle, but nonetheless adds to a person's cognitive load. It's a type of discrimination that is difficult to navigate and often hard to prove. Thick description (Geertz 1973), though, is a powerful tool with which to explain these subtleties.

JACK'S STORY

Anthropology is well suited to assessing student-teacher interactions. One of my goals is to understand how these experiences are connected to broader sociopolitical structures and societal attitudes. I want to convey what it's like to live these experiences. To that end, I will take you through a sequence of student-faculty interactions as told to me by Jack, who is blind. I interviewed Jack several times during his last semester in college. He was a sophomore and was deciding whether he would leave his school. He became agitated at several points as he recounted his experiences of the last year, but he assured me that he wanted to participate because he needed to tell his story. Jack has since dropped out of college.

I'll begin with Jack's physics class. One thing you should notice is that his situation worsened as his self-advocacy efforts increased. Self-advocacy is a point of pride for Jack, so it was jarring to him when it seemed to backfire. (Many people I spoke with are afraid to advocate for themselves because they feared that it would backfire on them as it did for Jack.) Jack said that physics is a difficult course to make accessible for screen reader users because it often requires a content expert, typically the instructor of record. Content expertise is the knowledge required to translate charts and graphs and accurately describe images, as an alternative format expert explained to me (Interview November 2019). Physics textbooks contain a plethora of equations, graphs, and other important visual information. When faculty don't participate as content experts, students can have delays in receiving their accessible materials. Therefore, when a content expert is needed, the student is at the mercy of their professor as to when, how, or even if they will get accessible materials.

Jack's physics professor refused to lend her expertise to the alternative format process. DS cannot force instructors to comply with their request, all they can do, as one accessibility coordinator told me, is to "massage their empathy" (Interview November 2018). Upon learning from DS that his professor was not willing to comply, Jack did what he knew best, what he was trained to do—he advocated for himself. Since his professor didn't want to provide content expertise to DS, he asked if she would just describe the specific images she was teaching from the book. She agreed. Jack said that just when he thought things were going to work out in physics, she started to get suspicious of his correct answers and refused to provide visual descriptions to him for future assignments. She thought that the visual descriptions gave Jack more information than his sighted peers. She thought it was cheating, an unfair advantage over the other students.

This suggests that the professor thought that Jack could only get the correct answers if he cheats. Even more, this interaction indexes higher education as an exclusionary space, one where difference is subjugated, in the sense of Franz Fanon, who writes, "I personally would say that for a man armed solely with reason, there is nothing more neurotic than contact with the irrational" (Fanon 2008: 98). One might argue that Jack's experiences with his physics professor are contact with the irrational.

Jack said that one of the most grating things his physics professor did was email his mid-term results to Disability Services and his academic advisor because she was so impressed by his high score. Thinking with Goffman (1963), when stigmatized people enter public spaces, they are overly scrutinized and minor failings are evidence of their stigmatized positionality while they are celebrated for accomplishing ordinary things.

Jack next successfully advocated for an assistant of sorts as an accommodation for his physics class. The idea was that this person would accompany him to his physics class and help him with homework and exam preparation. Well, this too soon led to more problems for Jack. According to Jack, his assistant "spent most of her time messing around on her phone" (Interview September 2018). What's more, Jack told me that she was rude and often hostile when she actually did the work of being Jack's reader/scribe. He didn't trust her to be his scribe for homework and exams because of the way she treated him. Certainly, some of her behavior was discriminatory. For instance, she wouldn't help him find accessible video tutorials, but also wouldn't describe the videos to him. Finally, there was fraud. She charged Disability Services 20 hours weekly but never worked more than ten. Ultimately, he dropped his physics course on the recommendation of Disability Services.

I'll pause here to point out that Jack's experience with a DS employed reader/ scribe is rare amongst people who participated in this research. It was startling to Jack because it was unique to his own experience. Its outsized impact on his college experience, however, demonstrates that even one bad situation can be devastating, and in his case, was the event that permanently soured his feelings about higher education.

In his second semester, Jack wanted to complete his foreign language requirement, so he signed up for a Spanish class. Unfortunately, Jack's experience in Spanish class followed a similar path to his physics class. For instance, he was required to use a totally inaccessible website. Here's a summary of his description of that website. The textbook was on a website that wreaks havoc on Jaws, Jack's screen reader. He said that as he was reading with Jaws, no matter where he was in the chapter, he was continually brought back to the beginning of the chapter. When that happened, he had to find his place and start over, only to find himself back at the beginning of the chapter again. There were other issues too. There were buttons with preprogrammed audio of people speaking in Spanish, which were inaccessible, but because of copyright issues, DS couldn't make them accessible. In addition, there was an assignment tool on the site that he could click to open, but he couldn't read anything within it. DS persisted and was able to make the textbook accessible, but that raised another issue.

Jaws doesn't enunciate like a native speaker, so it's difficult to understand because it's completely different than a person speaking. Jack had a braille display, which is a tool that translates text into braille, but Spanish braille is a bit different, so he had to learn new braille shapes. Finally, after more than half of a semester focused on accessing his Spanish course, he petitioned his school to let him take the course as an independent study. It became oral-based, speaking and listening only, meaning he got no instruction on Spanish writing, nor did he have the ability to use what he was learning in conversation, a common pedagogical tool in foreign language classes. Ultimately, he got course credit, but he didn't get out of the course what he had hoped to get.

How are student experiences complicated by unsupportive DS offices? Too often, student-DS interactions are overlooked when assessing disabled student experiences, as if DS is a benevolent force only capable of doing good. As I show below, though, DS has tremendous power over students registered with their offices, and as such, are an important variable to assess in student experiences.

Let's take Jack's math experience, in which Jack found himself with a supportive teacher but an unsupportive DS office. Jack was emphatic about how much he appreciated his math professor. "If I had a professor of the year award, it would go to my math professor" (Interview September 2018). Jack said that his professor spent a lot of time trying to think of ways to make the course more accessible. For instance, he created tactile graphs, allowing Jack to access materials without using his eyes. Still, accessibility barriers remained.

To gain full access to course materials, Jack needed to be able to use Jaws, his screen reading software, for his textbook. However, DS told Jack that math doesn't work with Jaws, so he would have to use NVDA, a different screen reading program. Eventually, DS would learn that Jaws, in fact, did work with the math book, so the time he spent learning NVDA was unnecessary.

Jack felt strongly that the alternative format specialist at DS was intentionally making his life difficult. "I know she doesn't like me. Probably because I didn't let her boss me around" (Interview September 2018). He told me that the quality of the accessible materials she sent to him was sloppy. There were a lot of delays and mistakes in the materials. He finally stopped bringing issues to her because she had become a pain to deal with. As Margaret Price argues, "Disabled people often choose to shut down or leave situations rather than continue dealing with the costs of those negative reactions, even if that means they don't get the access" (Price 2024: 119). In another instance, Jack told me that they have printed braille for him in the past that wasn't accurate or was crooked, but when he asked DS to fix the mistakes, they disagreed saying the braille was fine, even though they didn't know how to read braille themselves.

Jack dropped out of school at the end of his turbulent first year. His story illustrates the difference between policy and practice, what is supposed to happen versus what actually happened. Despite putting his extensive self-advocacy skills to use and despite having comprehensive academic accommodations, these weren't enough to counter the ableism and inaccessibility issues, and the corresponding cognitive load.

IT'S THE HARDEST THING TO EXPLAIN TO PEOPLE

Brittany introduced me to the term cognitive load. Until then, there was an elusive, nearly indescribable, source of socioemotional and physical stress amongst the majority of research participants living with disabilities. Brittany named these difficult-to-explain realities of living with a visual impairment as the cognitive load, noting that it's the hardest thing to explain to people. She described the cognitive load in her life as the brain power that it takes to work in-person. It's not a matter of transportation, it's not a matter of workplace accommodations, it's the energy, time, and mental and emotional burden that goes into ensuring that transportation and workplace accommodations are planned and executed. When she described the cognitive load, I thought that finally, someone had given a name to something that I had been seeing in my data.

Brittany is a visually impaired working mother. After earning her PhD, she stayed in academia for a few years but has now transitioned into the private sector, currently working for an educational research company. During the Covid-19 pandemic, Brittany's employer switched to remote work. Unexpectedly, she was less stressed and more productive. Intrigued, I asked her why, and she said that the switch to remote work had greatly reduced her cognitive load. But that reprieve was short-lived. After the Covid-19 pandemic, her supervisor wanted everyone to return to in-person work. Brittany advocated to continue working remotely. When she tried to explain why she wanted to keep working remotely, her supervisor asked her, “Why can't you just come in? We can just get you this cubicle, and we can turn the lighting off” (Interview November 2022). Brittany told her that it’s not as simple as that but struggles to find the right words. It’s an uncomfortable topic to discuss with your supervisor because it’s so personal.

Brittany tried to explain to her supervisor that there are things that weigh heavily on her mind, like riding the bus to work. But, she said, how do you convey the lived reality of that experience? There’s a lot that goes into riding the bus with a visual impairment, a cognitive load invisible to the world of the sighted. The task, then, is to make it visible. To do so, she described several examples for me to sketch here.

Brittany told me that she knows the bus system really well, so well that she knows that the system is unreliable. There’s supposed to be a speaker that announces the name of the bus to the people waiting at the bus stop, but it’s often inaudible, delayed, or turned off. So, she’s developed a habit of verbally confirming she’s on the correct bus by asking the bus driver. Once on the bus, there’s supposed to be another speaker that announces bus stops to the riders, but it too suffers from the same problems as the outside speaker. Sometimes, the speaker announces the wrong stops, so Brittany has developed a second habit, tracking the bus she is riding on her smartphone.

When a person can’t see, it can take a lot of mental energy and strategic planning just ensuring you get on the correct bus and get off at the correct stop, things that sighted people don’t need to think about. Once at the office, simple greetings and other social interactions can be overwhelming, meaning that even the social aspects of in-person work contribute to the cognitive load. Brittany is heavily reliant on her peripheral vision, so sometimes, she forgets to aim her eyes at people when speaking to them. People don't realize that she's talking to them. She feels like she's offended colleagues in the past who think that she's ignoring them when she doesn't acknowledge them when they pass each other. She can tell that she's passing someone but doesn't always know who it is or if they are smiling or waving at her. If she works remotely, she doesn't have to worry about those awkward social encounters. But it's hard to explain that to a sighted person. Margaret Price (2024: 151) describes it well: "Barriers can be terribly difficult to explain— and sometimes it's not easy to explain why they're hard to explain". Given that, people are strategic in how and when they advocate for accommodations.

Negotiating access, whether at work or in school, is an emotionally fraught process that involves confronting how people respond to disability, which are often negative or condescending interactions. As a result, people with disabilities typically use a cost-benefit analysis in deciding whether they will advocate for their accommodations. That is, the exhaustion of continual negative reactions and embarrassment can lead to access fatigue, a situation wherein people decide to forego accommodations rather than continuing to deal with negative interactions (Price 2024).

Just after her PhD, Brittany worked for an R1 university. In that position, attending in-person meetings added a lot to her cognitive load. Brittany told me about a time when she was part of a team that gathered in a new room each time they met. She explained that it was hard to focus on her work because she was too busy finding the meeting spaces and watching for hidden dangers, like unmarked steps. Price (2024) calls this disability admin. Disability admin is part of the cognitive load. Disability admin is specifically about managing impairment, from transportation to access. It's the logistical aspect of the cognitive load.

People with disabilities often arrive early to meetings because they need to figure out if the space has physical or digital access barriers. Locating unfamiliar meeting spaces and discovering potential access barriers during a meeting distracted Brittany from her actual work, and she spent more time per meeting because she needed to arrive early. As part of her current job, Brittany conducts interviews and focus groups, which when done in-person, pose their own set of challenges that amplify her cognitive load. She likes to get to interviews and focus groups early so that she doesn't have to find people, they find her. If she's meeting someone in an unfamiliar location, arriving early helps her find the right room and set up before anyone else gets there. During the interviews, it's sometimes difficult to focus on the participants because she's nervous about being able to see her interview questions. She uses large print so that she can look at her interviewees and refer to her questions and notes without too much of a distraction, but she worries that it seems unprofessional to be so obvious about reading from an interview script. Sighted people can be less conspicuous about checking their notes. Even so, she doesn't want to forget any interview questions, so she prints out her interview script as a backup. Should we assess Brittany's lived experiences as a form of inequality? In a word, yes. She bears an inordinate cognitive load compared to her sighted colleagues as a result of her visual impairment.

I'M A RECOVERING ACADEMIC

Sonya left her doctoral studies because the spark that initially motivated her had fizzled out. It was becoming too stressful and toxic. It was hurting her physical and emotional and mental health due, in large part, to her relationship with her advisor who she describes as deeply abusive. After Sonya had medical leave, her advisor stopped responding to her communications altogether. There was no explanation, Sonya says, just neglect then total abandonment. Losing that support made graduate school untenable because, as I show throughout this dissertation, the relationship between an advisor and advisee is a determinative factor in whether a disabled graduate student will complete their degree.

I asked Sonya if there's anything she wishes society understood about blindness, and I was surprised to hear her use the same phrase as Brittany to do so. "I would like professors to be aware of the implicit cognitive load that comes with being a blind student" (Interview October 2022). Note that Sonya chose to answer my question about society by directing her response toward professors. It speaks to her concerns about, and interest in, drawing attention to a gap in support for disabled graduate students. She told me that her professors understand at an intellectual level that things take longer, but they don't grasp how that plays out in her life. She explained it to me like this: "You were expected to be writing papers and presenting at conferences and trying to get articles published in your last year. If you're trying to navigate that and then write your thesis and get all your research material, it's continually rolling this ball up this hill [where] if one thing fell apart, it has the jeopardy of falling back down again" (Interview October 2022).

Sonya's story illustrates how only people who experience the cognitive load can understand it. It can only be known through lived experience. As we have seen, the consequences of this ontological incommensurability can be profound. Sonya's loss of support from her advisor coincided with her realization that DS didn't have the resources to support her access needs, which was the other reason she left her program. Specifically, they were slow in getting her accessible materials because they didn't have the resources to support her heavy reading load. She took on the burden of figuring out how to access course materials herself. "I took on all that responsibility of coordinating and acquiring and managing my textbooks, which taught me a lot in organization and in self-advocacy and things like that. But it was just another level of cognitive load. Right?" (Interview October 2022). Once again, Sonya uses cognitive load to describe part of her lived reality. Sonya's experience with DS indexes broader institutional barriers faced by disabled graduate students. In addition to the already cumbersome workload of a typical graduate student, students with atypical body-minds often bear a greater cognitive load because they have to participate in their own access needs. Sonya is pointing to an accommodation "blind spot" in higher education-inadequate resources for disabled graduate students.

A FINANCIAL DRAIN

The theme that emerged from interviews with DS directors, DS counselors/coordinators, alternative format specialists, and digital accessibility experts, is inadequate funding. Collectively, they operate on tight budgets that make supporting students a constant balancing act. Further, DS offices are under tremendous pressure from university administration to keep their costs down.

A November 2017 interview with the Director of Disability Services at a R1 university illustrates how these pressures shape the ability to provide academic accommodations. What follows is a summary of our conversation about his office's budgetary constraints, a conversation in which I was asked to mask the name of his institution. He told me that although certain disability types require more involved accommodations and therefore more resources (for instance alternative formatting) he is cautious in using that characterization when speaking with university staff and higher-ups because he doesn't want to give the impression that certain students are costly: doing so could jeopardize his ability to provide an array of important accommodations. Disability directors from other schools who he knows have told him that they have had a person above them try to calculate the cost per disability student. He worries that if that happened at his institution, it could create budget cuts because some students do incur a larger cost than other students. For example, it costs about $40,000 per year for an interpreter with a student on a 12-credit load. After salaries, his budget is about $200,00.00 for all other expenses. One full-time undergraduate student costs about 20% of that overall budget. I told him that it seems like a good argument to request more funding, but he said that university higher-ups would interpret these costs through a bottom-line lens. It's an ongoing struggle to justify current funding while also making the case that more resources are needed to support students with disabilities.

The neoliberalization of the higher education system means that disabled students are viewed as a financial drain. When a student's value is tied to whether and how much money they bring in or consume, disabled students become a burden, albeit one schools must bear to be in compliance with ADA laws. The result concretizes the status quo for disabled students. In the next section, I show how Diversity, Equity, and Inclusion (DEI) initiatives reinforce the status quo by returning to my own experience.

THE STRUGGLE FOR ACCESS

Diversity, Equity, and Inclusion (DEI) programs are propaganda to protect the privileged. This was the first thought I had after I got workplace accommodations as a Graduate Part Time

Instructor (GPTI) in the Continuing Education program. My accommodations were approved just before my third semester teaching. The GTPI program is intended to give advanced graduate students experience creating and teaching their own classes while also providing tuition assistance and a small monthly stipend. Prior to being hired as a Graduate Part Time Instructor (GPTI), I was a TA for other Professors. Advancing to a GPTI would strengthen my CV and give me crucial experience creating and leading my own course.

I was hired to teach in the Continuing Education program, so my course would be an asynchronous online modality, meaning I would have to use the Learning Management System (LMS) for every aspect of my course. As a TA, all I was required to use on the LMS was the gradebook. Now, I had to upload readings and other course materials, create learning modules, set up dates and times for assignments, create exams and discussions, and create lecture videos. It only took me a few hours to realize that none of these administrative tasks are accessible using a screen reader. I spent several days trying to figure out workarounds, but it was clear that I needed workplace accommodations.

I explained the situation to the learning management team that supports the Continuing Education program. To my relief, they told me they'd personally assist me with the inaccessible bits until my accommodations got approved. Obviously, this was not solving the situation, but it was a temporary workaround. At least that's how I understood their promise of support. Their supervisor, upon learning of their extracurricular work, said it was outside the scope of their job responsibilities to help me. They were required to stick to the letter of their job responsibilities. That meant that they could only offer guidance for instructional design, a foggy phrase that justified stopping the flow of any resources toward my accessibility needs.

While I had their support, I had been trying to get accommodations through the ADA office, but the ADA office didn't respond to my request until the middle of the semester. At my university, the ADA office handles workplace accommodations and DS handles student accommodations. I had approved accommodations through DS, but those only covered academic accommodations, so I was confused by the delay in my workplace accommodations with the ADA office. My cognitive load was threatening to overwhelm me, and my class felt like it could unravel at any moment because my time was spent trying to navigate the inaccessible LMS and advocate for my workplace accommodations. The meetings, emails, and other invisible labor of self-advocacy added to my cognitive load.

Once I contacted the ADA office, they told me that my supervisor in the Continuing Education program didn't think I needed an accommodation. In fact, he told them that I had rejected accommodations. For the next eight months, I continued to meet with the ADA office, and they continued to deny my requests based on my supervisor's explanations. Let that simmer. The ADA office was making decisions about my workplace accommodations based on my supervisor's opinion instead of working directly with me. His explanations, in my opinion, can be reduced down to ableism. He stated that I could only receive accommodations that were inside the framing of my job description. As a reminder, he had previously put a stop to the support I was getting from his employees. Why, then, would he undercut my request for workplace accommodations?

To some people, it is outside of their imaginary, inconceivable, that blind people are qualified to teach sighted people, as if we are intellectually penniless. While my experience is filled with ableism and topped with discrimination, the point of this vignette is to illustrate the cognitive load of these experiences. Despite having consistently high course evaluations and positive student feedback, my supervisor wouldn't allocate any resources to support my workplace accommodations. Junko Teruyama et al (2018), in their study of self-identifying teachers with disabilities in Japan, explain how these teachers feel they have to prove that they are competent, even when student outcomes for classrooms with disabled teachers are similar to student outcomes without a disabled teacher. Now that I have accommodations, my job feels precarious and I worry every semester that my contract won't be renewed. I do my best to go unnoticed so that I'm not perceived as a problem.

I was only able to access workplace accommodations after alerting my doctoral advisor and the chair of my home department about my ongoing struggle. Their support convinced the ADA office to provide workplace accommodations for me. It turns out that there is actually money to fund my specific accommodation. Yet, my accommodations were only approved after people stepped in on my behalf. As Sonya's experience above illustrates, not all graduate students have the same level of support from their advisors.

I began this section with a critique of DEI initiatives. In doing so, I am trying to strengthen DEI, not to do away with it. My experience shows how diversity, equity, and inclusivity are good to speak and perform but the changes necessary to actualize them will disrupt power structures and require resources, neither of which are willingly shared. As the situation currently stands, they want to invite us into their ranks but they don't want us to thrive. Frankly, the policies adopted by top administration around DEI work to improve the public face of the university are empty gestures unless those policies result in substantive improvements.

In order for higher education to be more equitable and inclusive of people with disabilities, we have to relieve individuals of the burden of accessibility and place it back on to the institution. To do so, it is necessary to reimagine access for people with disabilities in academia. Moreover, Chen et al (2023) discuss how DEI initiatives create a massive and invisible workload disproportionally borne by the marginalized faculty the programs are supposed to benefit. Many research participants echoed similar thoughts about DEI initiatives.

Diversity, Equity, and Inclusion initiatives have broken down many barriers for people with disabilities, but those achievements often conceal the remaining needs for many body minds who still face societal barriers (Dolmage 2017). Institutions of higher learning often make symbolic gestures or adopt progressive social policies, but the underlying socioeconomic structures of oppression remain intact. I build on Clara Han's (2012) concept of the performative break to describe the chasm between DEI initiatives and their actual impact on the lives of people who they proport to improve. Han develops the idea of a "performative break" from the past to describe how the Chillian government acknowledged the inequities that resulted from Chili's economic liberalization under Pinochet. For Han, this process is performative because it left intact the economic structures that led to inequalities. Similarly, DEI initiatives are often a performative break from the past because their small improvements don't change the underlying socioeconomic structures that create inequity.

CONCLUSION

This chapter has shown that disabled students don't have the luxury to muddle through. Muddling through is a privilege unknown to people who inhabit disability worlds. Margaret Price's goal in writing *Crip Spacetime* (2024) was to demonstrate that contemporary approaches to access in U.S. higher education actually increase inequity. They are worse than doing nothing. In addition, as I demonstrate, the social relations of students and faculty with disabilities, along with institutional views about independence and expertise, shape how people actually experience DEI initiatives.

In the first few chapters, I was primarily focused on visual disabilities. In the next chapter, I focus on hidden disabilities. One reason I do so is to demonstrate the generalizability of the concepts of crip time, independence, and the cognitive load beyond the disability worlds of the visually impaired to include cognitive disabilities, mental health disabilities, arthritis, mobility disabilities, and disabling chronic illnesses. A focus on hidden disabilities also allows me to assess whether and how people disclose their hidden disabilities, particularly within sites of higher education.

CHAPTER V

DISCLOSURE

This chapter uses ethnographic stories to explain the various ways that people disclose or mask their disabilities when they have an option to do so. For most people, disclosure and masking are not antipodal choices that, once chosen, becomes forever and everywhere their strategy. While true for some people, for the majority of research participants, a blending of masking and disclosing are strategically used according to the social context, demonstrating the fluidity of these choices.

The questions that guide this chapter are: How do self-advocacy and academic and workplace accommodations intersect with decision-making around disclosing and how do these decisions play out? I assess the interactions between people with disabilities and their professors, advisors, colleagues and supervisors, and Disability Services (DS) offices. To whom do people disclose and under what circumstances? Do they cover, or mask, their disability?

Disclosing your disability begins by acknowledging that you have one. To be sure, there is a process of acceptance when you become disabled. To bring you an insider's perspective on that internal process, I begin the chapter by explaining my own process of acceptance. In this narrative, themes of masculinity, stigma, and the concept of habitus are analytical tools I use to make sense of my own struggle with acceptance and disclosure of blindness.

TOXIC VENEER TO MASK THE FEAR

I pretended to be sighted for many years after I lost my vision. On those occasions when I had to whisper my secret, I did so with shame, and I'd usually minimize the truth about my blindness. I didn't use a white cane, and if I had to admit it, come clean as it were, I just said I couldn't see that well. I couldn't move past the idea that when people saw me with a white cane, the identity they created about me might not match the identity I imagined about myself.

The imaginary I created about myself was of a normal guy, a regular among the cool crowd, someone who fit in everywhere. The odd person who did snicker my way suffused my mind with shame. For years, my primary obstacle to disclosure was, well, myself, hovering in that space between my internal struggle of accepting my blindness while acting sighted and disclosing situationally, only when absolutely necessary. One reason that I struggled to disclose was due in part to the version of masculinity I had internalized. The only way to understand that version of masculinity is to put it within the sociocultural context of my youth, to peek into the earliest and most sedimented aspects of my habitus.

I kept up the masquerade for twenty years, clinging to a sighted past, refusing to accept my disability. It was my internal struggle that led to this research. In part as a result of my research, today I assert blindness as a part of my identity, most notably and materially marked by my regular use of the white cane. The most important reason I began using my white cane was to signal to other people that I'm visually impaired. It was an intentional shift from masking my blindness to highlighting it. I also use my white cane to navigate unfamiliar physical spaces. That doesn't mean I use my white cane every time I leave my house. If I'm going to dinner with my wife or going to my parents' house or, say, playing with my grandkids at the park, I choose not to use my cane. I use my cane for both social and practical reasons, but familiar places with familiar people reduces the need for it.

“WHAT I’M WORKING FOR IS SOMETHING MORE THAN FREE”

I come from a blue-collar family and a blue-collar town and I still have a blue collar heart.[1] It used to be a mill town until corruption brought it down. Burnt out factories with broken windows and brick skeletons are like headstones littering the river that winds through town. The industrial revolution made it a boom town, but the boom went bust as jobs disappeared across the industrial northeast.

My parents were raised in poverty. My dad was one of twelve children, most of whom worked to help the family survive. Life was about survival. The family could only scrape by if the children contributed their wages. My dad began working at age six, delivering newspapers in the freezing winters and dodging the ghosts of the filthy streets. Eventually, he found his way into the grocery business, where he became a store manager at age 23.

Because of his dogged determination, my brothers and I were the first generation raised in the middle class. Of course, part of yesterday’s man stayed with him, especially the value of hard work and toughness. Pierre Bourdieu (2002) gives us the concept of habitus to describe how the totality of a person’s experiences shape how a person acts in particular situations.

A real man is tough, he doesn’t cry, he provides for his family, and he is always climbing the company ladder. He is independent. When a person is disabled, however, it can be difficult to embody that kind of masculinity. As I was losing my vision, one of my main concerns was that I would never be a real man. Admitting that I had a disability automatically disqualified me from that version of masculinity.

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[1] Heading from Isbell, Jason. 2015. Something More Than Free. Something More Than Free. LP. Dave Cobb.

When my dad assured me that I wasn't disabled, I was just visually impaired, it really did quell those fears. He would tell me about successful blind people that he learned about, which helped me know that losing my vision wasn't a death sentence, not even a social death.

Problematically, I internalized an extreme version of this message, denying my disability and acting sighted. This strategy helped me navigate those early years, but it became exhausting. As I got older, tripping, falling, stubbing my toes and bashing my head hurt more and took longer to heal.

I have found that disclosure has improved my life, but everyone has unique disability experiences, so disclosure isn't the right decision for everybody. To disclose is akin to opening your robe, your secrets revealed. Disclosure means to bring the private sphere into the public (Pearson and Boskovich 2019; Toller 2021). The decision to disclose or not to disclose is stigma management. Oftentimes, disclosure and "performing disability" go hand in hand. Tobin Siebers (2004) explains that performing disability occurs when a disabled person acts out, or performs, what is expected by able-bodied people to prove one's disability. The cripple must play the part of a cripple, helpless and inferior, lest people become suspicious and insecure (Goffman 1963). In other words, disabled people inhabit societal stereotypes associated with their disability as part of the disclosure process. So, if someone discloses that they are visually impaired, but they don't appear to be so, nor do they use a white cane or have a guide dog, people may not actually believe that they are blind.

SELF-ADVOCACY: REINFORCING DISABILITY AS DEFICIT

Mary (who I introduced in Chapter 3, Cripping Independence) and I met at a coffee shop inside the main library on campus. She had her service dog, and I was using my white cane. I had only recently started using my white cane regularly and was still getting comfortable being seen with it. Mary ordered first. A black tea and a crunchy sounding pastry. I got my usual house coffee and made my usual mess of lids and cream before we found a small table. The music was not yet on in the café, so the tinkle of fingers on laptops, the conspiratorial whispers of students gossiping, and the beeping timers and occasional clanging of kitchen dishes filled the silences in our conversation.

I was interested in Mary's experiences as a blind student in higher education. I really wanted to focus on the process of academic accommodations once they were approved. What was it like working with faculty? How about DS? What were the differences between Mary's experiences versus the rights granted by the ADA?

Even if a student doesn't fear stigma from faculty, stigma from other students remains a concern. Emily Krebs (2019) explains that many students hesitate to request academic accommodations because their peers don't understand why they still need accommodations at the college level. These students don't want to be viewed as less than by their peers. Therefore, stigma management is always at the forefront of decision-making in social and academic environments.

If a person wants academic or workplace accommodations, they first have to disclose that they have a disability to the appropriate office (Price et al 2017). As a result, many people forego accommodations because they don't want to disclose their disability. Many people don't identify as being disabled, so applying for accommodations is often the first time a person identifies as having a disability. It is often the first step in self-advocacy in higher education, but it is only possible if you disclose.

The next step in self-advocacy is to set up a meeting with your professors to review your accommodations. Disabled students with academic accommodations are strongly encouraged (although not required) to meet with their professors before the semester to talk about their academic accommodations. It's the first time a student has to decide if they want to advocate for themselves and disclose their identity as a person with a disability. Consider that this process includes composing an email to request a meeting, the actual meeting time, and when meeting in-person as most participants did, the time includes transportation and navigating campus, both of which involve crip time and an additional weight to the cognitive load.

Mary does follow the guidance of DS and told me about why it has been useful for her. "I always send out an email to all of my professors explaining my disability and I usually ask a few questions about the course. Most professors appreciate it because they can make any accommodation requests to Disability Services before the semester" (Interview September 2018). The meeting helps the professor understand their responsibilities, and if there is anything they will need help to implement, they contact DS.

Not all professors understand their responsibility in implementing academic accommodations. For instance, Mary told me, "Sometimes, they don't let you get slides ahead of time because they claim copyright or some shit, so I have to educate them on it". When Mary says that she has to educate them, she means that she's got to advocate for herself.

When professors are reluctant, reacting by instinct, Mary explains why she needs the accommodation and then she walks her professor through their specific responsibilities. At this stage, Mary is still trying to build a bridge with her professor. However, if a professor continues to resist, Mary's next step is to get DS involved. From there, DS reaches out to her professor and "tries to talk sense into that person". It's only happened a few times to Mary, but you may be able to tell by her salty language that it's upsetting. Most of the time she gets the accommodation, but only because of her persistent self-advocacy. Mary went on to tell me that self-advocacy is really about building relationships. She learned that sometimes it's frustrating, and she'd never get some accommodations in place if she didn't effectively self-advocate. "It's exhausting", she said.

While Mary's story is an example of self-advocacy in the student-professor relationship, she and most other people in this research also advocate for themselves with their peers. One common strategy is asking friends and peers in class for occasional assistance. For example, several people mentioned asking other students for notes, help with physical assistance, and any number of things that accommodations don't cover or that professors forget to implement.

In an interview with a Division of Vocational Rehabilitation Counselor, I learned how crucial self-advocacy skills are to be successful as a person with disabilities. The counselor explained that people with congenital disabilities have 13 years of K-12 education to develop their self-advocacy skills. But for people who become disabled during the course of their life, the time to develop self-advocacy skills is reduced. For adults who become disabled, they are likely to only get about nine months of Orientation and Mobility/ Independence training at the most, and none at all for a broad swath of this group. She explained that the reason it's so important to develop these skills before the end of high school is that adults are expected to know what they need and how to get it, whether at school or in the workplace. In K-12, there's a lot of individual support for kids with disabilities. A lot of them have a paraprofessional walk them to classes, they have assistance getting their lunch, among many other things (Interview July 2022). Self-advocacy, then, is a skill that is essential when those supports suddenly go away.

Self-advocacy is a new experience for most people starting a college degree because academic accommodations are guaranteed in the public K-12 school system, but unevenly guaranteed in higher education. In the K-12 education system, students with a medically diagnosed disability qualify for a customizable curriculum as mandated by the Individuals with Disabilities Education Act, but the same guaranteed protections are unevenly implemented at institutions of higher education (Saunders 2020; DVR interview July 2022). Faye Ginsburg and Rayna Rapp (2024) explain that guaranteed accommodations for K-12 students must be provided in a timely manner, but in higher education, students lose parental advocacy in educational contexts that don't have the same protections as K-12 schools.

It is the responsibility of the student to navigate this uneven terrain, so advocating for academic accommodations is a crucial skill to hone. Therefore, the meeting between professor and student is a negotiation where people with disabilities creatively assert their disability expertise in ensuring their own access needs are met. Academic accommodations aren't automatic, they're a negotiation whereby students educate their professors about how to implement accommodations and allay concerns expressed by the professor.

In this research, I have found that the reality of self-advocacy is that it leads to people with disabilities being responsible for their own accessibility needs. However we may feel about this model of education, and the continuous, exhausting need to navigate insufficient accommodations, effective self-advocacy is an undeniably foundational skill for people with disabilities.

Self-advocacy is an individualized approach that creates a perception that disabled students have a skills deficit. After all, it implies that a student is unable to succeed in a course because there is something wrong with them. It pays scant attention to the broader social environment within which students actually advocate for themselves (Woolf and Aliase de Bie 2022). Instead of creating widespread institutional changes that address accessibility barriers, schools use the individual accommodation model to mitigate access barriers, eschewing the responsibility for institutional change. I describe self-advocacy as paradoxical, because of its perpetuation and reinforcement of disability as a deficit while simultaneously being, inarguably, an essential skill for people with disabilities in higher education.

Self-advocacy is, moreover, a continuous process requiring repeated labor (Bruce 2020), adding tremendous weight to a person's cognitive load. I argue that self-advocacy is a form of symbolic violence (Bourgois and Schonberg 2009; Horton 2016). It makes people internalize their perceived subjugated status in the social hierarchy. The basic fact that a person has to advocate for themselves means that they are appealing for acceptance into the dominant group, acceptance that is contingently and unevenly granted. Because disabled people are bombarded with the discourse of self-advocacy, albeit by well-intentioned people, they misrecognize this hierarchy as natural. Even though effective self-advocacy skills lead to more access, self-advocacy is a vehicle for symbolic violence that perpetuates the actual subjugated status of disability. Self-advocacy is often experienced as symbolic violence because it is internalized as natural and necessary, instead of recognizing the inequity that it creates.

FORCED DISCLOSURE: APPROVED ACCOMMODATIONS, SKEPTICAL ADVISOR

Academic accommodations don't tell teachers why a student requires accommodations, and they don't reveal private medical information. They inform teachers which accommodations have been approved. They're non-negotiable. While most students with disabilities who participated in this research told me that although most of their professors are supportive, many people also described negative experiences with at least one professor. Further, several disabled students I worked with for this research told me that their graduate advisors wouldn't accept accommodations approved by Disability Services. They demanded to review their students' medical records themselves and then make a decision on which accommodations would be approved. Kelly's story is the most blatant example.

When I met Kelly, she was writing her dissertation. Kelly chose to attend her university because it was one of the only schools that offers her specific subfield within the social sciences. As Kelly described how her vision and traumatic brain injury (TBI) affect her, she used specific experiences in which they affected her graduate training and reminded me that her symptoms and experiences are true. She needed to make sure I was convinced because people are initially suspicious of TBI, even dismissing it as some cockamamy new-fangled diagnosis. In her response to my recruitment email, Kelly had indicated that she wanted to share several ableist experiences.

Kelly is a white woman with a traumatic brain injury and low vision. Neither of her disabilities are apparent. Kelly doesn't require the use of a white cane or guide dog, and according to sighted people, she doesn't look like she has low vision. Her vision is such that her primary accommodation for low vision is large print. When that's not an option, she uses a screen magnifier, and for printed materials, she uses a handheld magnifier.

Kelly is one of several people who spoke with me about surviving a TBI. TBI experiences varied between research participants, but they all shared a combination of permanent or episodic symptoms, both sensory and or cognitive symptoms, fatigue and or painful headaches. Kelly told me that her committee doesn't believe that she has a TBI. Even when TBI survivors disclose, they are often met with skepticism and doubt. The TBI survivors in my research experienced much ableism, stemming from pre-conceived notions of TBI.

Kelly teaches in a disability related field and hopes that her story will help stop this kind of treatment of disabled students. I asked her, “If you were to experience discrimination, do you feel you have the resources to address it?” “That’s a tricky question”, she said. “This is confidential and anonymous right?... Because I’m not quite out of the program”. She said that she knows the resources available on campus, but the issues she has faced have been within the department. “I’ve had experiences where I didn’t feel comfortable reporting because I didn’t want it to hold up my degree progress. It was a real fear to me”. She then asked, “So specific reference to departments won’t be included right? I’m the only one in the department with a vision issue, so they could identify me”.

My question had unnerved her, but she also seemed to feel like it was a kind of permission, permission to finally tell her story, a story that she kept secret out of fear of retaliation. I told Kelly that I could give her a pseudonym and confidentiality.

The possibility of retaliation weighs heavily on a person’s decision to report abusive or discriminatory behavior. The fear is palpable. Indeed, several participants in this research had to leave their graduate school before graduation precisely because of toxic relationships with their advisors. Some of these participants have even switched disciplines.

Kelly’s experience highlights the tremendous power that doctoral advisors wield over their advisees. Disabled graduate students don’t have the same reporting protections as undergraduate students. Graduate advisors are the boss, they are the judge, sometimes your friend and confidant, the bane of your existence and your only hope to finish this dream. In this research, many graduate advisors shattered dreams. Kelly had one of these advisors.

She was preparing to take her comprehensive exams and successfully applied for reasonable academic accommodations through Disability Services. She went through the application process, which is burdensome in its own right. She was shocked when her doctoral advisor didn't accept her accommodation letter. Kelly would have to submit her medical records to the graduate committee who would decide which accommodations Kelly would receive. Kelly pushed back explaining that's not how the process works, but the department said it was the only way she would get accommodations. It's important to point out that none of the people on the graduate committee had medical or disability expertise. Under duress, Kelly finally submitted her medical records to her entire five-person doctoral committee because she was afraid that continuing to resist would delay her progress through the program. Kelly's department also seemed to have a bullying problem. Kelly said, "I heard about other students being bullied until they left the program and I wanted to avoid dealing with that". Kelly experienced forced disclosure as a scarring violation of her privacy but feared retaliation so much that she didn't make an official complaint. She spoke with Disability Services about the incident who urged her to report it. She told them that she would, but only after she graduated.

In spite of stories like Kelly's, my research is in line with Cynthia Bruce (2021) who explains that most university faculty have generally positive attitudes towards supporting students with disabilities. But my research shows that assessing the experiences of students with disabilities in higher education through quantitative data sometimes obfuscates the lived realities of those experiences. Even one difficult professor can impact a student's overall well-being in numerous ways.

Kelly said that the previous story was the most flagrant experience she endured, but daily microaggressions piled up. Professors consistently forgot that she couldn't see small print so wouldn't bother to read any small print on their presentations. She'd advocate for herself and remind the professors, but they'd tell her not to worry or that it was already past, so it didn't matter. It wouldn't impact her grade in the course. There's exclusion behind this seemingly harmless statement—the favor that missed work would not impact a course grade—so I want to linger on this for a moment.

Professors hold disabled students to a different standard than other students when they don't hold them accountable for the same amount of work. Of course, professors think they are doing these students a favor. But the other side of the argument is that it is exclusionary because disabled students don't get the same information as other students, even if they've paid the same tuition for that course. Equally important, though, is that this behavior is demeaning and infantilizing. It is one of the most common microaggressions experienced by people who participated in this research.

Kelly was made to feel constantly othered, as if her department were trying to reinforce her differences. Her committee often joked with her saying, "If you're disabled, I don't know what that makes us!" The words made it seem like they were trying to complement her, as if she is doing a remarkable job. "But it never felt good. It felt like they were saying I was doing a great job hiding something" (Interview July 2018). Since the committee making these compliments also didn't believe that Kelly actually had disabilities, these comments are felt as ill-intentioned jabs. "There is a lot of distrust, like I am trying to get away with something". She had to re-provide documentation affirming her disabilities. "I don't know why getting large print makes me some kind of bandit". To her professors, Kelly looks fine, but she is continuously asking for assistance. It was exhausting to keep educating her department about her disabilities.

Kelly prefers to keep her disabilities private, but since she has hidden disabilities, teachers forget that she has accommodations. As a result, she has to remind professors repeatedly, subjecting herself to probing private questions. As we see, then, self-advocacy means that people need to disclose potentially hidden aspects of their identity. For many people, disclosure is highly contextual. People explain that it can be embarrassing to disclose, so they are strategic in their disclosure to manage potential stigma.

I want to draw attention to a theme that begins with Kelly's story and is carried through the next several stories. People who disclose hidden disabilities can spend a lot of time convincing people that they are telling the truth. When someone doesn't fit into a person's mental schema, people get suspicious and demand proof. Even when presented with proof, many people remain skeptical and unbelieving.

"IT'S LIKE I'M BEING PUNISHED FOR BEING DISABLED"

Susan is an Asian American who uses they/them pronouns. At the time of our interview, Susan was working on a PhD in Anthropology. Susan has multiple episodic, unpredictable, invisible disabilities including rheumatoid arthritis, migraines, ulcerative colitis, endometriosis, complex PTSD, anxiety, and depression. Like other people I spoke with, Susan doesn't want you to have pity or feel sad for them. It is important to them that you know they live a good life. They do, however, want to share these experiences to raise awareness around academic ableism, and they want to highlight the inordinate power that advisors have over their advisees, which I argue, locks disabled graduate students into a precarious position.

Susan experienced arthritic flare ups that severely impacted their mobility and required them to take medical leave several times while in their previous doctoral program in Psychology.

Susan has all of their medical records that confirm all of their diagnoses, and they disclosed their disabilities when they applied to their graduate program. Still, they had to explain to their advisor whether their absences were due to arthritis, colitis, or a mental health issue. With a great sigh of exasperation, they explained, “It’s like emailing my bowel’s diary to my advisor” (Interview November 2019). It was humiliating. Susan’s self-advocacy seemed to have no effect on their advisor.

Susan and their advisor were working on several publications together, agreeing to be co-authors. However, Susan’s name was removed from these publications, even though Susan had done the bulk of the writing, because she didn’t accept that Susan’s extended absence was due to disability. Susan told me, “It feels like I was being punished for being disabled”. During this particularly difficult arthritic flare up, Susan’s doctor called their advisor to explain that her student had been hospitalized and would need some time off. Their advisor asked to speak with Susan, who was lying in a hospital bed, and told them not to come back to the program. Shortly thereafter, Susan’s advisor successfully lobbied the department chair to get them dropped from the program. I asked them how they would characterize their overall relationship with their advisor, and they responded: deeply abusive.

Although Susan was eventually able to find a welcoming discipline and supportive advisor, their traumatic past has made them question their self-worth and place in academia. They ask themselves, “What the fuck am I even doing here? Do I fucking belong?” For Susan, a few good experiences can’t erase an ableist system. Disclosure and self-advocacy were fruitless, and highlighted their marginalized identities, harmed their well-being, and negatively impacted their sense of self-worth.

JUST BECAUSE YOU DISCLOSE DOESN'T MEAN WE CARE

Jane has been diagnosed with several cognitive disabilities: complex PTSD, anxiety, depression, ADHD, dyspraxia, and identifies as being on the Autism spectrum. Jane's story exemplifies how graduate school is designed for a specific kind of learner, one who embodies the "normate" body-mind. As someone who has an atypical body-mind, Jane struggled to manage her workload of graduate courses, research, and teaching. She told me that it takes her longer to process information, and she describes her ADHD as so intense that she can no longer drive because she's been in five car accidents she attributes to a total inability to focus. Still, she tries to mask her disabilities whenever possible.

In graduate school, starting and completing assignments became a daily battle that she mostly lost. On average, she estimates, it can take her three times longer than her classmates to complete assignments. She turned things in late, struggling just to stay afloat, but her record of high grades illustrated quality work. In her first annual review, Jane was told that the department had confidence in her intellectual ability, but concerns amongst faculty were raised about her ability to complete work on time. It was clear that Jane would have to disclose or possibly be dropped from graduate school. To thwart stigma, Jane has typically chosen to mask her disabilities, but she's felt compelled to disclose recently because of the overwhelming cognitive load of graduate school. "I've always felt the need to hide and 'pass' because societal discrimination fed me the perception that my intellect is correlated with my mental health" (Interview November 2022). This time, however, Jane needed accommodations, which meant she would have to disclose to Disability Services and her department faculty. But, instead of access and support, Jane was met with stigma and ableism. Her worst fears of disclosure proved to be prophetic. Applying for academic accommodations can be stressful, but it's not supposed to cause distress. For Jane, however, applying for academic accommodations was "traumatizing". Jane had never previously worked with a Disability Services office, so she didn't know how the process worked. It was her understanding that she was supposed to explain the specific kind of help she would need as part of the application process. So, she explained how her disabilities impacted her writing and asked if she could have someone help her with editing her papers for typos and formatting. DS told her that they don't meet personal requests, and they didn't make a decision on her application. Jane felt like DS was "gaslighting" her, offering nonsensical excuses and using demeaning language in their email responses. Finally, after months of delay, DS made a decision on her application. Denied. Denied because they didn't quite believe that she had a disability, despite the medical proof in their possession.

Disclosure doesn't guarantee accommodations. Occasionally, disclosure can backfire, potentially increasing a person's vulnerability. In fact, Jane's decision to disclose began a sequence of events that culminated in her leaving academia. "I left academia because of the ableism", she said.

Disbelief can turn into discriminatory behavior. Now, I turn to Bri, who never discloses her disabilities because she fears losing her job if her department were to learn of her disabilities.

"SHUT UP AND GET OVER IT!"

The sharp angle of the November sun cast long shadows across the downtown Vancouver waterfront. The briny smell of the harbor was tinged with the perfume of the coffee and bread wafting from a café, the smell of French fries on the next corner, a cigarette from an open car window, and the hint of a joint from someone walking ahead of me. The city was alive, breathing its rhythms into my bones.

I shook off that revery as I entered the hotel and anxiously waited for Bri. She had agreed to an interview if we could meet away from the conference where there would be a smaller chance of being recognized by other anthropologists. Another condition that we worked out ahead of time was that she would get a pseudonym and that I would do everything possible to make sure that nothing I wrote could be connected to her. I also knew that she was going to tell me something deeply personal and traumatic. I was about 15 minutes early, so I took a seat on a lobby chair. Realizing that my chair was really a side table, I nonchalantly found a real chair, hoping nobody saw the blind guy sit on a table. I sat, red-faced, staring at the floor, watching the shoes pass by.

Bri arrived in the lobby with a whoosh of cool air from the chilly day. She greeted me with a smile and guided me over to the hotel restaurant. She insisted on buying me a cup of coffee when we sat down. The coffee arrived and she began, covering my hand and saying, "I want to say thank you for doing this work" (Interview November 2019). Bri was neither the first nor the last person to thank me for my research. As the researcher, I thank everyone for participating. After all, it is their time and their deeply personal stories that I am asking them to share with me. Their gratitude reflects hope that their stories spread awareness and encourage change.

Bri reminded me that she does not want, and cannot have, any association with anything I write. She's afraid that if people learn she has disabilities, they will use it against her with personal attacks and professional consequences. She currently deals with a lot of bullying and harassment based on her race and gender, and she's certain it will get worse if they learn of her disabilities. I would be the first person to whom she discloses. Despite the anxiety she felt about disclosing to me, she had been looking for a way to talk publicly about her experiences, so that's why she chose to share her story. Interviews are opportunities, offering space to share stories in an anonymized setting, often for the first time, and knowing that these stories will live forever through their publication.

Bri has depression and complex PTSD. She said, "There's not enough attention on experiences like mine and I know there have to be other academics out there like me who have had horrific experiences or have had their tenure impacted" (Interview November 2019). Bri wasn't eligible for tenure until her thirteenth year and doesn't want other people to experience that kind of delay. Awareness, she feels, can be a powerful tool to aid that effort.

Bri began by telling me about the Indigenous Studies Center at her institution, a source of tremendous pride for her. Despite its promising potential, Bri told me that white faculty were highly resistant to an Indigenous Studies Center and there was a lot of pushback towards female Indigenous hires. As an Indigenous woman, she inhabited the image of their ire.

Bri has dealt with several panic attacks while teaching. She told me that when she covers topics with violence, it can trigger symptoms associated with PTSD. She explained to her department chair that some of the topics she was being asked to teach were upsetting because her own family directly experienced some of the violent historical events covered in class. He told her to "shut up and get over it". Even so, she will not disclose to her department colleagues because she is scared that they will use her disability against her. I asked her how she tries to navigate the situation, and she told me that she seeks guidance with a spiritual healer and spends time in a Long House to try to avoid getting overwhelmed.

Recently, Bri had to take medical leave while she was fighting ovarian cancer. Like her disabilities, she kept the reason for her medical leave private. Upon her return to work, she was disquieted to learn of a rumor claiming she took leave because she had had a nervous breakdown. The narrative was already concretized in her colleagues' minds as a fact by the time she returned to work. In fact, her department chair met with her to discuss her medical leave. In their meeting, he recommended that Bri find a different career because academia is not a place for people who have mental health problems. It is certainly ironic that, given her determination to mask her disabilities, Bri experienced discrimination due to mental illness while dealing with a totally separate medical issue.

She explained, "The university wants representation, but it polices that representation differently than white faculty". These race and gender-based forms of discrimination affirm Bri's decision not to disclose her disability. She said "when people learn you have a disability, they use it against you".

Race and gender play an important role in Bri's experience. Disability disclosure is always entangled with other identity markers, including race, gender, academic rank, and so forth. Unfortunately, higher-education policy and practice usually operate according to an individual model of disability, which assumes that individuals must disclose, negotiate accommodations, and thereby obtain access (Price et al 2017). Many BIPOC scholars with hidden disabilities echoed the same sentiment in our conversations; they don't disclose to their colleagues because they are often accused of fabricating disabilities as an excuse for their perceived laziness. Bri's experience is a clarion call to embrace the politico-relational model of disability. It would greatly reduce the burden of disclosure. The current, individualized approach means that the decision to disclose for academics remains a risk-reward analysis, weighing the potential support and workplace accommodations versus possible stigma and retaliation (Brown and Lee 2020).

Bri's story is important because it highlights the unique experience of navigating disclosure while also facing discrimination based on race and gender. The stakes are high for Bri, with profound consequences to her mental well-being and professional livelihood. In the next, section, I introduce Paul, who lives with the same stakes, but in his case, it's because his colleagues don't believe him.

THE INTERLOPER

I had met Paul several times at the American Anthropological Association (AAA) annual meetings. Most recently, he reached out to me at the 2023 combined Canadian Anthropology Society/AAA meetings in Toronto. He's a research participant and mentor, often using our conversations to offer me guidance in navigating academic life with a disability. Our plan was to meet up after a late morning panel, but we didn't have a specific place to meet up because it's easier for Paul to contact me when he's ready rather than planning ahead with a specific place and time. It's a strategy he uses to cope with the sensory overload he experiences at conferences.

Coincidentally, we attended the same panel where he found me after it finished. We caught up for a few minutes among the cacophony of anthropologists swarming the halls. Paul suggested we find a quiet place to talk, so I followed him down an escalator and then another and then down a wide hall where he found an empty bench. Away from the buzz of excited anthropologists, it was clear that he wanted to get something off his chest.

He nodded across the expanse of the convention center hall and said that the quiet room is over there. He described it as nothing more than a storage closet. It had no windows. It had a small table with two chairs that faced each other. "It's drab and dreary like they just emptied out a storage closet" (field notes November 2023). In my mind's eye, I pictured a single light swinging from an exposed chord, cigarette smoke drifting past his eyes. Was it an interrogation room? Aiming my eyes at a door I couldn't actually see, I imagined an unmarked room hidden in the shadows. Paul said it shows how much they care about people like him. "They just do something, so we'll shut up". Paul feels like the conference organizers don't value people with disabilities and points to the quiet room as exhibit one. His statement also tells me that Paul made an accommodation request to the conference organizers for a quiet room, which is in itself a choice to disclose.

Paul explained how vital the quiet room is an accommodation for him at professional conferences. He told me that it's the only way to manage his traumatic brain injury (TBI) symptoms because conferences cause sensory overload. Sensory overload, in turn, is highly disruptive to his conference experience. He misses planned panels and meetings, and his TBI symptoms get worse, as I expand on below.

Paul told me that he doesn't feel welcome within the community of disabled scholars, like he's an interloper. Paul is a heterosexual white male and TBI is not a visible disability, so he feels like other disabled scholars are suspicious of him, as if he's trying to infiltrate some elite club. It was evident to me that Paul felt like his identity worked against him. Since his disabilities are hidden, they aren't available for scrutiny. Put another way, Paul feels like he would be accepted by the disability community if his disabilities were apparent. That said, I want to offer a bit more insight into Paul's perspective.

Over the course of several interviews, Paul told me that a lot of TBI survivors live alone, and that they tend to have few friends and not much of a social life. In fact, he acknowledges that his social skills contribute to his perceived exclusion from the broader community of disability scholars. Paul's disability world collides with the normative academic world.

Paul's brain injury is so extensive that symptoms change all of the time. Aphasia, double vision, trouble focusing, hemispheric numbness throughout his left side, and his reasoning skills are his most common symptoms, but their severity is fluid, influenced by stress, sleep, food, and other socioenvironmental factors. There are myriad ways that his symptoms can impact his work. He gave me a few examples from the conference we were both attending.

Double vision affects Paul most when he's stressed. He gets very stressed at professional conferences because of sensory overload. So, the morning before his presentation, he began experiencing double vision. He told me he couldn't get through an informal reading of his presentation because the double vision got so bad that he kept losing his place.

One of the reasons Paul experiences sensory overload is because there are so many different noises so he can't focus on the sound he is supposed to be hearing; instead, he hears a chorus of indistinguishable sounds. "So, you could be speaking to me, and I would hear everything, but I wouldn't understand a word you were saying" (Interview November 2019). These examples demonstrate why the quiet room accommodation is so important to Paul.

Discussions about accommodations have been a consistent theme in my conversations with Paul. During our first meeting in 2019, Paul was finishing his PhD. When Paul disclosed his TBI to his professors, he told them how his symptoms are episodic and unpredictable. As an example, he would explain that he can sometimes have no symptoms, be able to speak clearly, but then at other times, abruptly at times, he can't speak at all. Likewise, he informs them, aphasia can impact his writing, making his words jumbled and confused. Aphasia can also cause writing to take longer. Clearly angered by the memory of his recent experiences, he said that instead of asking how they could work with him, they pushed back, asking why he thinks his symptoms present as they do, criticizing how he described his impairments. We should understand this as a clear example of ableism (Dolmage 2017). His professors trivialized his disability experience, and even questioned how he disclosed his disability. He told me it's as if they're saying "TBI isn't a big deal" (Interview November 2019).

In that initial conversation, Paul went on to say, "When I would talk to faculty, they would assume that I had a psychological condition. Then I would say, no, it's not trauma in the emotional sense, it's trauma in the medical sense, like blunt force. When I would explain that, they wouldn't necessarily accept it, and they thought of it as some weird newfangled diagnosis that came out of the Iraq and Afghanistan wars because TBI is of course the signature wound of those wars. After I explain all the stuff to them, they just don't care".

By our next meeting in 2023, Paul had become a tenure-track faculty member. Despite this, his colleagues also seem to interpret his disability according to their own beliefs and attitudes about TBI. What is more, they use those interpretations to conclude that Paul isn't disabled. He said that those colleagues seem to think that he's just unable to handle the work of an academic. Some of them have told him that he's getting an unfair advantage because he requested workplace accommodations.

The "unfair advantage" response to academic and workplace accommodations has stung most of the people who participated in this research. It was also interesting how often research participants with disabilities used humor to demonstrate their more absurd experiences. Several people told me that their colleagues and faculty act as though accommodations are like a massive conspiracy perpetrated by the disabled—from their words I imagined disabled academics gathering late at night in undisclosed locations to slurp their glut and count their loot. The ubiquity of the "unfair advantage" response requires analysis. What is behind this belief?

The goals of U.S. universities are increasingly designed to meet the needs of the service economy, so that teaching and non-instrumental knowledge production are replaced by a singular focus on producing a product, the student, to meet the needs of a service economy. This transition has meant that education has shifted from a goal to transform society to a position where education is removed from other social territory to meet the employment demands of corporate America (Gordon 1995). The often-repeated refrains, “I don’t have time to deal with accessibility” or “it’s not my job”, reflect the effects of these fundamental changes within U.S. universities because they index specific discourses and actions that align with the corporate university system. When faculty refuse to implement accommodations because they feel like it gives students an unfair advantage, the faculty are highlighting a culture of hyper-competition, even among students. The fact is disabled students require accommodations to succeed in an ableist society. Accommodations are not an unfair advantage; they merely try to get the person closer to an even playing field. Still, institutions focused on individual success and hyper-competition inevitably exclude many groups who don’t fit the normate figure (Thompson 2007). You’ve got to fit the system because it won’t mold to your needs.

Using Foucault’s genealogical method, Michael Skyer (2019) found that the ADA legitimized governmental control over disabled bodies through the discursive category of disability. In fact, celebratory events and rhetoric surrounding its passage focused on how the ADA would bolster national productivity. Problematically, however, the ADA created the structures by which the government could regulate and categorize disabled bodies (Skyer 2019). By defining disability as abnormal, the ADA marks the boundary of the normal. By doing so, the ADA concretizes societal assumptions about disability instead of reducing them.

As a faculty member, Paul has to decide whether he will disclose his disabilities to his students. He decided to disclose to his students about aphasia once, and only because he didn't want them to speculate about why he occasionally stutters, slurs, or when he seemingly has trouble focusing. It didn't go well. He told me that they didn't respect him after that. Once he disclosed to them, they would shout out words during lectures when they thought he was stuck, trying to guess the correct word. Inevitably, it got to a point that they'd holler out even when he paused to clear his throat or paused to let something he said soak in the brains of the students or just pause to collect his thoughts. After that experience, he stopped disclosing to his students.

Shortly after that experience, Paul took medical leave. His TBI symptoms were intractable, causing him to fall behind in his work. During that leave, he sought out rehabilitation that taught him strategies to navigate moments of aphasia. He said that these strategies make students none the wiser, totally ignorant of his struggle.

INVERTING ADHD

Among people I spoke with who have a cognitive or mental health disability, Jacob is unique. Whereas most people don't disclose those disabilities, he discloses, and does so strategically. Jacob has an accommodation for flexible assignment deadlines because it takes him longer to complete coursework. The accommodation for flexible assignment due dates allows Jacob to maintain a full course load, thereby preventing any delays in his progress to graduation. What's more, he is able to turn in his best work.

Jacob doesn't have a favorable opinion about other people with ADHD. He feels like there are a lot of people with ADHD who use it as an excuse to turn in late or missing work. "I don't like to use ADHD as an excuse, but I know when to ask for help" (Interview November

2019). He feels like a lot of people would rather just blame ADHD for their bad grades because it's easier than getting accommodations and doing the work.

He has mixed feelings about living with ADHD. He told me that stereotypes about people with ADHD are misleading. "It's not that we can't focus, it's that we focus on what's interesting to us". If there's a topic that's interesting to him in school, he tends to excel in that course. But topics that are not interesting to him are a struggle and he falls behind quickly. During class, he tends to tune out topics that aren't interesting to him and has trouble completing coursework and studying. The impacts snowball: he has to spend extra time outside of class trying to learn what he missed in lectures but doing that also puts him further behind in the already-assigned coursework.

The flip side of his hyper focus when the topics are interesting is that his intense focus can be socially isolating. "I can fail to understand other people's perspectives because I get totally stuck on one thing", he explained. Consequently, he has difficulty working in groups or participating in online discussions.

Jacob's use of disclosure as a strategy indexes a person who has become an expert in his own disability experience. He understands how ADHD impacts his productivity and ability to adhere to timelines, and as such, he made a choice to disclose his disability to maintain a heavy courseload that will ensure he doesn't have delays to graduation. Disclosure, then, is a form of self-advocacy for Jacob.

“THE QUEEN OF HIDDEN DISABILITIES: SELF-ADVOCACY AND THE ARTHRITIS LOTTERY”

Peggy Sue wears several hats. She is a PhD student, part-time adjunct faculty, and works part-time at a museum. Her story illustrates the strategic use of disclosure to manage stigma. She discloses her physical disabilities related to arthritis but doesn’t disclose her learning disabilities. Her experience exemplifies the complexities of navigating the tricky terrain of disclosure, self-advocacy, ableism, and stigma, neatly tying together the key topics of this chapter.

Recently, Peggy Sue was diagnosed with a learning disability that she characterizes as an auditory processing disorder: “In my hearing ear, sound waves are incorrectly translated on their way to and from my brain” (Interview January 2020). Her learning differences are problematic for classroom learning, which requires listening, so the classroom is often a difficult environment for hearing students with audio processing disabilities. Like many people with cognitive disabilities, Peggy Sue only discloses that part of her identity to people she trusts and only if she must.

As a child, her parents didn’t want her to admit that she had a disability, so she didn’t identify as being disabled until she began graduate school. Until recently, she’s been ashamed of her learning differences, always afraid that she would embarrass her parents if her secret slipped out in polite company. It is one of the reasons she still worries about disclosing her learning disability. Peggy Sue grapples with managing stigma, internalized by years of denying her disabilities, while also accepting her learning differences so that she can access academic accommodations. In the beginning of the chapter, I explained that disclosure begins by first acknowledging that you have a disability. For Peggy Sue, that acknowledgement took decades.

Peggy Sue was one of several people who participated in this research who told me that they couldn't access resources available to disabled kids in K-12 school because their parents refused to accept and therefore disclose their children's disability. As a result, these participants tell me, they had self-esteem issues because they lagged behind other kids in school. It is interesting to note that these people were happy and empowered once they were diagnosed as adults. The diagnosis put their childhood experiences in different context, but also because they learned about resources available to them.

Peggy Sue has an approved accommodation for extra time that she qualifies for based on her learning disability. It was an accommodation specifically intended for her comprehensive exams, but when it came time to take the exam, her department chair denied her extra time accommodation. He said it would be unfair to other students. Peggy Sue didn't want to disclose the nature of her disability to him, so she tried to get Disability Services to advocate for her.

A few months before this interview, Peggy Sue's extra time accommodation was dropped altogether without warning or explanation. She said that it seemed like her department was retaliating against her because she had dared to advocate for herself. She had sent several emails to Disability Services over the previous few months, with no response.

Peggy Sue's doctoral program requires her to be proficient in a second language. Until DS does respond and re-implement her accommodation, she can't take her language proficiency test, and therefore, can't enter candidacy. To invoke an anthropological phrase, she is in a kind of liminality, betwixt and between (Turner 1969). Meanwhile, her struggle to get an accommodation for flexible assignment due dates got caught up in the amorphous cogs of institutional bureaucracy. DS required her to get a new medical exam because she was requesting a new accommodation. She had to pay $200 for a doctor evaluation even though she was already approved for other accommodations. She submitted the doctor's evaluation several months before this interview. At the time of writing, she is still waiting to hear back from Disability Services about an accommodation for flexible assignment due dates.

Peggy Sue also had an approved accommodation to record lectures, but she uses that accommodation sparingly because she has to pay for the transcriptions herself. Disability Services only approves her accommodations, they don't assist with transcription. The success of this crucial accommodation is based on Peggy Sue's ability to pay. This accommodation is important because it allows her to use her strength as a visual learner by converting lectures and translating them into a readable format. She told me that even when she can afford the transcriptions, there are teachers who won't let her record their lectures. For example, in a small graduate seminar, her professor wouldn't allow her to record class because he claimed that doing so would be an invasion of the privacy of other students. She insisted, and he partially relented, asking the entire class: "Does anyone mind if Peggy Sue records our conversations? It's supposed to help her disability" (Interview January 2020). After some discussion, he decided to modify the accommodation and asked a volunteer to send Peggy Sue class notes.

"I was so self-conscious. It was like everyone was staring at me. I know I shouldn't feel this way, but I want to be normal", she told me. By making such a public announcement, the professor had violated her privacy by informing the class of her disability. As this example demonstrates, sometimes disclosure is out of your control.

In addition to her learning disability, Peggy Sue grapples with physical disability as well. She sprinkles in a healthy dose of self-deprecating humor to describe her disabilities. "I won the arthritis lottery", she quipped (Interview January 2020). She explained that she has several different forms of unpredictable episodic arthritis that cause mobility impairments, pain, and fatigue.

Peggy Sue wanted me to understand that arthritis doesn't just cause mobility impairments, it hurts. The intensity of the pain is consistent, only dulled by medicine if you're lucky enough to have access to insurance and a doctor. The pain alone is exhausting, so arthritis requires a lot of rest. Rest means missing work. Therefore, arthritic flares result in crip time from both mobility impairments and from pain induced fatigue. Moreover, arthritis is largely hidden until it flares up, so people get confused when she uses mobility aids. After all, she may have been walking fine the last time a colleague saw her.

Peggy Sue manages stigma by strategically disclosing that she has arthritis. She gets anxious about using mobility aids because she knows people judge her. By disclosing, she feels more comfortable using those accommodations and avoids stigma. In her experience, she has been less stigmatized for physical disabilities compared to her learning disabilities.

During student orientation a few years earlier, she disclosed her physical disabilities to her peers because she needed to use a golf cart to get to each building and felt like she needed to justify her use of the cart. Her arthritic flare ups primarily target her legs, and there is no visible reason for her to use a golf cart. Peggy Sue told me that she ordinarily discloses to people when she's using a mobility aid, so nobody thinks that she's just lazy. Here we can see how her earliest attitudes towards disability creep into her current decision-making process.

In the classroom, Peggy Sue discloses that she has arthritis to her students. As a graduate teaching instructor, there is an expectation that she stand and walk around the room, which is very difficult to do with arthritis. Additionally, she has to take a lot of breaks when grading and prepping for class and she falls behind in grading and getting comments back to students. By disclosing, her students can adjust their expectations around grading and class lectures. Heather Dawn (2017) discusses how decisions to uncover, or disclose, are often done to assert disability identity. To make that identity clear to others, and therefore, disclose their disability, people often do so slowly and repeatedly to normalize their disability.

Peggy Sue used all of her paid sick-time for arthritic flare-ups, so when she gets sick with the flu or a bad cold, she has to choose between taking time off without pay, or working through her sickness. She tries to make-up for lost time when she feels healthy, so her good days tend to be busy catching up or getting ahead on upcoming work. In this sense, crip time means working fast on your good days. Leah L. Piepzna-Samarasinha (2022) makes the point that there is a sense of urgency for people with disabilities to work fast and hard because they don't know when they'll be slowed down again by disability.

Peggy Sue occupies a disability world of visible and hidden disabilities. She discloses some aspects of her disability to access academic accommodations and to manage stigma. Disclosure, for Peggy Sue, depends on the social situation. Her story also highlights issues of the cognitive load, crip time, and independence.

CONCLUSION

This chapter presented a series of ethnographic sketches that illustrate a diversity of perspectives about the idea of disability disclosure. The decision to disclose a disability is a personal one. These ethnographic sketches illustrate what goes into these decisions and the result of those decisions.

I've shown, through my own experience, as well as through Jacob's story, how disclosure can be the key that unlocks a door to possibilities. At the other end of the disclosure spectrum are Kelly, Bri, and Peggy Sue, who keep all or some of their disabilities private, where violations of that privacy have been traumatic. For other people, like Paul, disclosure leads to heightened scrutiny. Susan and Jane show that disclosure may also be weaponized to cause harm.

This chapter is focused on a very broad topic, disability disclosure, but you will also have observed that the overarching themes of crip time, independence, and the cognitive load emerge as well. I've pointed to those concepts here and there, but you the tools to spot them whenever they bubble up in a story. Those three themes are always active in people's lives.

Stigma is an ugly presence in this chapter. It was important for me to attempt to illustrate what it's like to experience stigma, its felt reality. I feel a responsibility to do so because of the emotional impact it had on the lives of my interlocutors. Stigma harms a person's mental health and can jeopardize a person's professional career, hence, stigma management is part of everyday decision making as it relates to disclosure.

In the concluding chapter, I shift my lens from disability to the consultants and administrators who advocate for Universal Design for Learning (UDL) as solution to accessibility problems. Their attitudes toward accommodations shape the experiences of the people you've met throughout this dissertation. Despite the promise of universal accommodations that would eliminate the need for individualized attention and even disclosure, I show the ways that UDL advocates neglect key aspects of personalized accommodations that actually meet the needs of people with disabilities.

CHAPTER VI

CONCLUSION

Throughout this dissertation, I've presented ethnographic stories that highlight how time, independence, and cognitive load impact the lives of people with disabilities. I've made the case that these factors must be addressed to achieve actual access for people with disabilities in academia. In this Conclusion, I now focus on Universal Design for Learning (UDL) because it is widely accepted that UDL will play an increasingly prominent role in classrooms. What is more, the goal of UDL is to phase out individual accommodations because, advocates argue, UDL will eliminate the need for them. I argue that, while UDL will reduce the need for many individual accommodations, people with disabilities have unique accommodations, specific to their lived reality, that UDL is unable to replace. The goal of this concluding chapter is to highlight barriers to implementing UDL and to interrogate what its proponents promise and assess the realities of its efficacy.

Is Universal Design for Learning helpful for people with disabilities? Should we adopt UDL and move away from individual academic accommodations? These questions are framed as a seemingly simple binary, but the reality is that some combination of UDL and individual accommodations is necessary because UDL creates more access, not total access. UDL creates a good foundation, but some individualization is still necessary. Disability is a fluid experience (Abrams et al 2024) and neither UDL nor individual accommodations completely account for the fluidity or relationality of disability. In this concluding chapter, I assess the realities of the efficacy of Universal Design for Learning through discourse and practice of consultants and trainers, knowledge and attitudes by professors, and experiential knowledge from people with disabilities.

This research has changed how I feel about UDL. When I first began this research, I didn't plan on interrogating UDL because UDL experts led me to believe that UDL would make everything fully accessible to me. In fact, I did their bidding, polishing its image, beckoning people into its inclusive arms. I had surrounded myself with pollyannish UDL evangelists. In my mind, the only remaining barrier to digital accessibility was the broad adoption of UDL. As such, my initial inquiries were geared toward understanding why professors weren't adopting it into their course design. That is, until I spoke to disabled people and experts in digital accessibility.

WHAT IS UNIVERSAL DESIGN FOR LEARNING?

Universal Design for Learning was inspired by the Universal Design philosophy in architecture and product design (Grant and Perez 2018). In its architectural origins, the focus was on designing structures that were navigable to everyone. Ramps and automatic doors, for instance, create access for people who use wheelchairs, but they are also useful for parents with strollers, or people who are carrying a cup of coffee in one hand and using a white cane with the other. Universal Design for Learning applies a universal design framework as a pedagogical strategy that aims for flexibility in student engagement, course design, and student evaluations (Dolmage 2017). UDL is rooted in findings from neuroscience, in which brain scan imaging shows how, while performing the same task, learners' brain activity varies a lot between people, so teaching to a statistical "average" learner is incongruous with how people actually learn.

UDL was originally intended to increase access for marginalized learners, learners who had needs that couldn't be addressed in traditional classrooms that taught to a statistical normal student. But, by categorizing students who didn't fit that figure, a figure of the student with "special needs" emerged. The category of special needs came into being only because of a statistical average learner. UDL re-imagined the traditional classroom by keeping all learners in the classroom instead of segregating those who didn't match the normate learner.

One of the primary arguments that supports adopting UDL is that it disrupts the current approach to teaching. As Kendra Grant and Luis Perez (2018) explain, people learn to become compliant with current teaching and have to conform to those norms lest they be marked as deviant and requiring special attention. Rather than recognizing the many ways people learn as a basis for pedagogy, traditional teaching is geared towards a statistical average learner. Consequently, most children are disciplined into a specific educational norm by the education system. The statistical average student is not disabled. They are neurotypical, white, middle class (Doolittle 2017). Rosemarie Thomson (1997) explains that the figure of the "normate" is a social figure by which individuals try to discipline themselves. It is comprised of a powerful assemblage of subject positions that a small minority of people actually possess. It's a mutually reinforcing dynamic whereby the existence of one requires the existence of the other. The purpose of UDL is to smash the normate figure and offer new inclusive pedagogical possibilities. The idea behind UDL is to teach diverse ways that people actually learn, as opposed to teaching to the normate learner.

Institutions develop disability and accessibility policies and practices based on either the medical or social models of disability. The medical model holds that the disabled individual is flawed and requires fixing through rehabilitation or some other medical procedure, whereas the social model holds that the social and physical environment is disabling (Freidner 2020; Kafer 2013). Among experts and professors, UDL is couched in the discourse of universal access. These ideas fit neatly within a social model of disability. It suggests that changing the learning environment can create near total access for all learners. Yet, it crucially neglects individual accessibility needs.

In her book *Feminist Queer Crip* (2013), Alison Kafer argues that the medical model is rooted in ideologies of overcoming disability and that a future with a disability is no good future. While the social model has been effective in reducing social and physical barriers, leading to greater social inclusion for people with disabilities and making disability legible as a social category (Freidner 2020), the social model is critiqued for paying scant attention to the ways that disability actually impairs people. The model that does account for individual impairment is the political-relational model of disability. The tenants of this model include taking into account intersectional experiences and the sociopolitical and physical context (Kafer 2013). In my research, I use a political-relational lens to explain why UDL, like the social model, is insufficient to meet the needs of disabled people.

Put simply, individual accommodations try to fix people while UDL tries to fix the learning environment. Yet while UDL addresses the learning environment, it doesn't consider individual disability experiences, nor does it consider intersectionality (Ginsburg and Rapp 2020). According to Kimberle Crenshaw (1989), who coined the term "intersectionality", the oppression experienced due to (for example) race *and* gender is much greater than oppression experienced due to race *or* gender. In this research, it was common for people to describe the intersectionality of living with multiple disabilities.

Some people are born with disabilities while others develop or acquire disabilities over the life course. Some disabilities are temporary, and some are permanent. They can be episodic and unpredictable. Some disabilities are visible to others while others are hidden. When considering these factors in combination with variables such as socioeconomic backgrounds, different educational backgrounds, different academic interests, in addition to varying levels of knowledge about and access to resources and technology, we can see how the accessibility needs of people with disabilities is highly individual even without factoring in multiple disabilities. When multiple disabilities are present, they are often mutually reinforcing.

Hannah, who you met in the chapter on independence, was recently diagnosed with ADHD. "Having a visual disability and ADHD is a bad combination", she told me (Interview August 2023). Hannah said this in the context of a broader conversation about her first semester in graduate school. She told me that she prefers to use a screen magnifier in combination with an audio reader for reading because she is a visual learner. Yes, people with vision disabilities can be visual learners. What does that mean in the classroom?

First, comprehending and retaining information presented in lectures is very difficult for Hannah. Because she can't see the front of the classroom, she has no image to associate with what she's hearing. She has a lot of trouble retaining information and staying focused when she only uses a screen reader to access readings. Oftentimes, accommodations for people with visual disabilities include a reliance on audio solutions, but for Hannah, that's not a realistic accommodation.

It is fatiguing for her to use her eyes, and she estimates that it can take her up to one and half times longer than a sighted person to read something. The extra time it takes Hannah to read is, of course, crip time. Because she is a visual learner, Hannah will always be a slow reader. A UDL framework would potentially include flexible due dates for all students. That would be helpful for her, but she would still read at the same pace and still experience fatigue. It is precisely these complexities that people with disabilities fear will be lost with the widespread adoption of UDL, unless specific individual accommodations are also still maintained.

The dearth of funding to Disability Services reflects the real value of people with disabilities at these institutions. I spoke with the Director of Disability Services at three different universities, and they all told me about the ways that their tight budgets impact how they make programmatic decisions about their services. Effective use of UDL would eliminate the need for some individual accommodations, and UDL also reduces the need for disability disclosure and academic accommodations (Brown and Leigh 2020), but it's expensive. For example, automatic accurate captioning of all visual media (a possible UDL solution) eliminates the need for providing captions for individual students. However, universities save money by maintaining the individual accommodation model because training faculty and creating the structural changes necessary to have automatic accurate visual captions is more expensive than maintaining the current ad hoc approach of providing captions for individuals. Cynthia Bruce (2021) argues that focusing on individual accommodations allows institutions to neglect to provide the resources that support UDL initiatives. It's cheaper to maintain the status quo.

Patty Douglas and Alan Martino (2020) argue that we need to rethink education altogether to make disability legible as a fundamental and valuable part of life. In other words, we should value people with disabilities and take seriously their experiences instead of continuing with the status quo, which is to (often minimally) meet legal obligations. UDL faces resistance to its implementation from faculty, but there are also budgetary constraints that act as a barrier to a more widespread adoption of UDL. I argue that these factors, resistance and budgets, has led to UDL experts using hyperbolic discourse about its benefits to generate interest.

The first person I interviewed with a disability told me UDL is a sham and it’s going to leave disabled people behind. I didn’t take it seriously. I thought that they were probably just jaded, which I could understand. But in the next interview with a different person, I got an even stronger negative reaction to UDL.

Shelly was quite adamant that it would be harmful to her. “I have very specific accommodations that UDL won’t cover. It’s idealistic, not realistic”, she emphasized (Interview December 2019). Shelly was an accessibility coordinator for a professional conference at the time of our interview. She is also neurodivergent and has physical disabilities and has an understanding of UDL through her own lived reality. She, therefore, has both topical expertise and disability expertise (Hartblay 2020). She has a holistic knowledge of UDL.

There’s a big difference between what Shelly would like to do as the Accessibility Coordinator and what she can do. She is constrained by the boundaries of her job description. Some organizations she’s worked for have empowered her to make sweeping changes, but others have limited what she can do. Another constraint to always having a perfectly accessible conference is that the location of the conference changes from year to year for most professional organizations. Each place has its own unique physical qualities, as well as numerous uncontrollable and unpredictable variables. A further major limitation is resources, both money and labor. Lastly, she explained that people also have unique disability experiences that require individual accommodations that any attempt at UDL won’t capture.

Shelly is skeptical about the efficacy of UDL. She said that UDL can actually elide the disability community, with other communities taking its place, because disability is not a central focus of UDL. So, while she does use certain aspects of UDL, she finds more guidance in the disability community itself. My conversation with Shelly gave me a new perspective on UDL. Even though she was talking about UDL in the context of professional conferences, her nuanced articulation had clear implications for UDL in the classroom.

We can also look to other sociocultural contexts to assess how UDL has been taken up. In the early 2000s, Japan adopted a policy of that included Universal Design into its basic plan for disabled people. The policy was intended to facilitate the physical access of disabled people across Japan's public transportation system. With the success of that policy, the state expanded the scope of these projects to include public parks, roadways, and other public places (Bookman 2024). However, the promotion of Universal Design didn't improve accessibility for many disabled people. Although the economic costs of renovating inaccessible buildings led some owners to cut costs by putting barrier free zones in remote areas, at its core, Universal Design didn't facilitate greater access for disabled people because of an utter lack of awareness amongst the public. Elderly people, parents with strollers, and other people monopolized the access points for their own use. The lack of attention on the access needs of people with disabilities mirrors that potential pitfall in UDL.

CONSULTING IN UDL

To this point, I've been focusing on UDL theory and practice. Now, I want to turn my attention to UDL consultants, the people who develop and/or train professors how to use UDL in their courses. Among UDL consultants, there are differences in opinion on its benefit to disabled students. This variation is the result of inconsistent UDL books, training workshops, and classes. Whereas some people understand that UDL creates a good foundation, but some individualization is still necessary, others feel that it eliminates the need for accommodations altogether. None of the staff that I interviewed who train faculty on UDL have a degree or certificate in UDL. They learn on the job through their own diligent research, by attending conferences and workshops, and by adopting common UDL models.

Charlotte had no formal education or training in UDL or Digital Accessibility. Yet, in this role, she designed and led UDL trainings for faculty and staff across her university. Because of her position of power, Charlotte was considered an expert and many of her methods were adopted by well-intentioned faculty and staff. In fact, faculty and staff who were trained by this UDL Consultant defined and implemented UDL principles differently than other UDL experts I spoke with, who follow more systematic UDL principles described in books like *Dive Into UDL: Immersive Practices to Develop Expert Learners* (Grant and Perez 2018). For instance, in order to develop trainings that would make Power Points and other digital platforms accessible for screen reader users, Charlotte had informal meetings with low vision and blind students who used screen readers, to ask them how they preferred content to be created. The compensation to the student for this information was a cup of coffee.

This approach does not take into account whether these students are using standardized screen reader navigation or if they are using “workarounds” to creatively navigate inaccessible spaces. A workaround is when a screen reader user draws on their disability expertise to navigate inaccessible websites and digital documents. A workaround is not always an option, and they are highly individualized. Using individual preference instead of changing the learning environment itself is in opposition to UDL principles.

At a different university, I interviewed another UDL consultant. She told me that she understands the perception that there is no way to make a course totally accessible to everyone. Even as she did so, she pushed back a bit against that perspective by pointing to the broader benefits that UDL can have for all students. "If a student has time and a half accommodation for tests, why not change how the test is taken so that all students have as much time as needed. Instead of having students take a 10-minute test at the beginning of class, tell them that they have as much time as they need to complete it" (Interview March 2019). This example highlights the difference between equality and equity. Equality is based on providing the same resources and opportunities for everyone. Equity, on the other hand, recognizes that some people are disadvantaged from the start and require individual resources to achieve equal outcomes. So, while it is likely that allowing everyone to take the entire class period to complete a ten-minute quiz will eliminate the extra time accommodation for some students, it may not suffice to ensure that all students achieve an equal outcome. My argument is that UDL is based on an equality approach and is a key reason that people with disabilities feel like their unique individual needs won't be addressed with UDL.

A few minutes later in the interview, I asked how UDL is able to meet the unique needs of disabled students. This consultant answered by offering me an example: "The goal of UDL is to create expert learners by encouraging students to be part of the why and how of fair learning. For instance, they can set personal learning goals short and long term. Students and professors then work together to meet those goals, and the goals are modified as necessary. As they achieve short term goals, they give presentations to their class so that they can facilitate broader learning with their classmates" (Interview March 2019). I note that requiring a presentation seems to violate the flexibility standard of UDL. In fact, allowing people to submit assignments in line with their learning style and abilities is fundamental to UDL pedagogy.

I have known Paula for a few years. She met with me for multiple semi-structured interviews, and I attended several of her public workshops and presentations. Her goal is to get

UDL into all classrooms. She said it would eliminate the need for individual academic accommodations. Her excitement was palpable, even infectious, and convincing. She said that digital accessibility should be built into course creation, but she only trains people to create headings, use alt. text for images, upload accessible readings, caption videos, and correctly label links. Even though those are useful guidelines to follow, I argue that digital accessibility involves more than the course learning management system. Total accessibility that would eliminate the need for academic accommodations is much broader than the digital environment. Digital accessibility experts that I spoke with explain that UDL does not focus specifically on digital accessibility, and thus UDL consultants are often underequipped to provide comprehensive training in this complex field.

Paula intentionally exaggerates the benefits of UDL to get faculty buy-in. She feels like instructors are more willing to learn basic UDL and digital accessibility if they don't have to also worry about academic accommodations. Even though there may be a rare circumstance when a student needs an additional accommodation not covered by UDL, she's confident in asserting that UDL will eliminate the need for accommodations. Still, in the neoliberal university, UDL promises a lot but may not actually deliver (Dolmage 2017), which may have the opposite impact: professor frustration.

PROFESSORS AND UDL: MISPERCEPTIONS AND MISREPRESENTATIONS, RESISTANCE AND RELUCTANCE

Freda, an Instructional Designer who tries to implement UDL in her training, is a UDL pragmatist, aware of its limitations and careful about how she describes it. When she told me how reluctant professors are to learn UDL, she said, “that’s a big reason why UDL trainers use hyperbole. They’re trying to sell it” (Interview January 2022).

There’s a lot of resistance to learning UDL from faculty. Freda explained to me that faculty tell her they “don’t need the training because they don’t have any students with disabilities in their course” (Interview January 2022). She said that a lot of professors refuse to use flexible student evaluations. For instance, Freda explains that a dyslexic student would benefit from being able to submit a film instead of a paper, but a lot of professors tell her that “students shouldn’t be in their class if they can’t do the work like the other students” (Interview January 2022). When she was training a professor on captioning his course films as part of UDL, he told her that “if a Deaf student can’t take my class, then they can’t get a job in this field” (Interview January 2022).

Several professors that I interviewed echoed the same kind of resistance as Freda described. For example, Dr. Geo told me: “I’m not going to teach to the bottom 10%. I’m not going to slow down because they can’t keep up” (Interview September 2018). A math professor for decades, Dr. Geo doesn’t feel it’s his responsibility to make his course materials accessible, a common sentiment expressed by interviewees, albeit not always so eloquently.

Faculty buy-in for adopting UDL in their course design is very low. In their guide to UDL, Kendra Grant and Luis Perez (2018) show that gradual release of responsibility for creating classroom access can be reduced when UDL principles are intentionally planned and explicitly shared with students, reducing the time faculty spend on access. Here, Grant and Perez try to assuage the concerns of educators who feel implementing UDL is a time burden, a common barrier to faculty buy-in. In my research, Digital Accessibility and UDL consultants use UDL as a gateway to teaching Digital Accessibility to faculty. These consultants also tell faculty that once they've created a course with UDL principles, their work is done. They don't have to worry about UDL or digital accessibility in the future either. Therefore, faculty logically feel like they no longer have to worry about implementing individual accommodations.

Professors who have had some UDL training told me that adopting UDL eliminates the need for academic accommodations. By using hyperbolic discourse, UDL Consultants effectively nullify the individual supports provided by Disability Services without replacing them. This sentiment is embodied in phrases like, "One size fits all" (Grant and Perez 2018), or "[UDL] tries to create enough flexibility for everyone so there is no need for accommodations" (Accessibility Consultant interview March 2018). Because of their own awareness of the insufficiencies of UDL, professors with disabilities that I interviewed expressed frustration about being required to adopt UDL, whether in the classroom or at professional conferences.

THE ACCESSIBILITY GAP

UDL is heavily reliant on the use of technology. People with disabilities often use assistive technologies to access digital environments. More technology must be better for people with disabilities, right? Wrong. I'll start with a few basic truths. Technology is not a panacea for digital accessibility. Newer is not always better. Digital technology is not inherently accessible unless accessibility has been built into the technology from the beginning. There is an accessibility gap between always advancing technology and accessibility.

Always advancing technology means that the learning environment is constantly changing. As such, students and faculty are always adapting to those changes. However, digital accessibility is rarely built into new technology. It is often addressed after the product has entered the market (Interview June 2022). As a result, people who use assistive technologies may not have full access to new products for several weeks. When I say full access, I mean that students can be excluded from full participation in the course, they can fall behind in their courses and focus their intellectual energy on learning how to access new technology rather than on the course material.

I have found that one reason the accessibility gap exists is because there is a lack of awareness and training around issues of accessibility, even for the most basic of tasks. For instance, professors are typically totally unaware of the need to only use accessible technologies in their classrooms. Several digital accessibility experts told me that it should be a basic principle that you ought not adopt new products into your course until they are accessible. Yet, most of the professors I interviewed have either never thought about digital accessibility or they feel that it is the student's responsibility to figure out how to use course tools and materials.

My second point is that the accessibility gap exists because it takes time for people to learn how to use new technology. That's true for everyone, but it's much more complex for people who use assistive technologies. Even when professors use accessible new products, it takes students who use assistive technology longer to learn how to navigate new websites or use new technology. The accessibility gap exemplifies the inescapable nature of the cognitive load as well as the role of crip time.

Many students with disabilities who participated in this research are concerned that UDL will banalize their experiences out of existence. They are afraid that when UDL is implemented, there won't be a mechanism for their unique individual needs. These students live on crip time and bear the weight of cognitive load in ways that UDL can't address. People with disabilities actually prefer a mosaic approach, plucking the best bits from UDL and individual accommodations.

UDL is the source of access friction. One interviewee told me, “Conferences are starting to make presenters create presentations as universally accessible” (Interview December 2022), which doesn’t consider if the presenter has the ability or knowledge, has the time or other complicating factors. That interviewee also noted, rhetorically, “why should they do it if there is a possibility that nobody in the audience even needs universal access?” (Interview December 2022)

In August 2019, I attended a conference on teaching and learning at my home university. I was there as a participant observer, observing conference accessibility and to learn about the newest research in teaching and technology. As I walked into the first panel, which had the promising title of “Effective Teaching Practices”, I was invited to pick up a handout from each stack spread across the table in the front of the room. Papers in hand, the panelists asked me to take a look at three posters set up around the room. They promised it would become clear why I should look at these posters during the panel. When I explained that I couldn’t see the handouts or the posters on the wall, bringing my white cane to eye level as I did so, they assured me I could get them in digital format after the presentation. This meant that I would be excluded from fully participating as an audience member. I sat through their panel and as I left the room, I smiled at the panelists while I dropped their handouts into the recycling bin.

Later on, I attended a talk led by the UDL Consultant who you know as Charlotte. She was going to give a talk about UDL. Here are my field notes from that talk. “Paper handouts were passed around the room. The handouts were referenced several times in the talk. A colleague sitting nearby asked if there were digital copies of the handouts and was told that Charlotte would email them to her later. Next, Charlotte asked the audience to discuss images on a power point that she didn’t describe, even after she was asked to do so by the same person.

When the audio went out, she said that it shouldn't be a problem as the video was closed captioned, leaving anyone with a visual disability to use their imaginations". She did, however, briefly touch on making syllabus and course documents accessible.

After the talk, I approached Charlotte with the other audience member who was also visually impaired, which was apparent because she uses a white cane, so we could give Charlotte our email addresses in order to receive her materials. Charlotte explained to us that the talk was not accessible because she was too busy ahead of the talk, as if that's a perfectly reasonable excuse. What does it say when a UDL consultant fails to use any UDL principles for giving accessible presentations?

CONCLUSION: BROADER CONTRIBUTIONS TO THE FIELD OF ANTHROPOLOGY

Overall, my dissertation contributes to theory and methods in disability anthropology, specifically in offering micro-ethnographic perspectives on the lived realities of people with disabilities in academia. My most significant contribution to disability anthropology is how I make vivid disability worlds (Ginsburg and Rapp 2013; 2024) through narrative storytelling. I contribute to the concept of disability worlds by showing how people use their individual disability expertise to navigate the ableist structures of academia and to bridge the gap between accommodations and actual access. In so doing, I build on the theory of refusal (Simpson 2014; McGranahan 2016; Reese 2019) by refusing the "suffering slot" narrative (Trouillot 1991) that portrays people with disabilities as having a deficit. This refusal is generative because it frames disability as an important part of human diversity that offers creative resources.

Further, this research shows how time, the concept of independence, and the socioemotional stresses of living with disabilities are important aspects to assess in examining disability worlds. I contribute to the concept of cripping independence (Abrams et al 2024) by presenting the creative ways that people use disability expertise and interdependent relationships in order to live independently.

My experiences as a blind graduate student also contribute to the literature in autoethnography and patchwork ethnography (Gunel et al 2021) through multiple methods of autoethnographic analysis, in-person and remote interviewing, and participant observation. This approach made it possible for me to interview more participants because we didn't always have to be in the same physical location. Since there are so few academics with disabilities in one specific location, remote interviewing allowed me to reach a greater number of participants. I also contribute to multi-sensory ethnography (Howes 2021) by illustrating how people use multi-sensory engagements to live independently. Together, my methods contribute a disability perspective to the decades-long struggle to decolonize academia, which has been led by female BIPOC scholars (Harrison 1991; Behar and Gordon 1995; Bolles 2013; Navarro et al 2013).

In 1991, Faye Harrison wrote a blistering critique of the ways in which anthropology is complicit in perpetuating neocolonial power structures that solidify a white minority at the top of the hierarchy. In 2021, Erin Durban expanded on the project of decolonizing anthropology when they strongly argued that anthropological fieldwork is ableist. Anthropological methods are premised on an able-bodied researcher, which is a major barrier for students with disabilities. This research has demonstrated my journey through that ableism and how I traversed those barriers. My research methods and analysis are strategies for conducting accessible fieldwork. More broadly, the stories I've shared demand that we reimagine higher education to be more inclusive of people with disabilities.

This dissertation contributes to the decades-long struggle to decolonize higher education in the U.S., which has been led by female BIPOC scholars (Harrison 1991; Behar and Gordon 1995; Bolles 2013; Navarro et al 2013). Decolonization within higher education means the intentional exposure and disruption of the structure of racialized and gendered power that continues to marginalize BIPOC, LGBTQ, and disabled academics and the knowledge they produce (Behar 1995, Bejarano et al 2019). Decolonizing higher education to be more inclusive of people with disabilities means dismantling academic ableism (Dolmage 2017).

By including my experiences throughout the research process, I am inserting my voice into the struggle to decolonize academia. Historically, people with disabilities have been the object of study, not the people who produce knowledge about disability (Dolmage 2017: 15). Whereas my blindness is ordinarily perceived to be a problem that needs fixing and a barrier in my social and professional life, digging into my experiences is one step toward this objective of decolonization. As such, my blindness also becomes an asset.

Academia is a contested space between past and future, tradition and change, theoretical dogma and paradigm shifts. New ideas lead to knowledge that strengthens, questions, and challenges what we think we know. The same tension plays out between academic ableism and access for people with disabilities. The inequities of contemporary academia are normalized, reinforced, and protected. This research shows that contemporary policy and practice intended to create access for people with disabilities in academia perpetuates the inequities it proports to prevent. These stories are compelling because they exist, and claim space, in spite of these inequities. Accessibility is only possible if we are guided by the experts who inhabit disability worlds.

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