



# Living Disability Theory: Reflections on Access, Research, and Design

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## ABSTRACT

Accessibility research and disability studies are intertwined fields focused on, respectively, building a world more inclusive of people with disability and understanding and elevating the lived experiences of disabled people. Accessibility research tends to focus on creating technology related to impairment, while disability studies focuses on understanding disability and advocating against ableist systems. Our paper presents a reflexive analysis of the experiences of three accessibility researchers and one disability studies scholar. We focus on moments when our disability was misunderstood and causes such as expecting clearly defined impairments. We derive three themes: ableism in research, oversimplification of disability, and human relationships around disability. From these themes, we suggest paths toward more strongly integrating disability studies perspectives and disabled people into accessibility research.

## CCS CONCEPTS

• **Human-centered computing** → **Accessibility theory, concepts and paradigms.**

## KEYWORDS

accessibility, autoethnography, disability theory, disability studies

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## 1 INTRODUCTION

Over the last decade, the prominence of disability studies in accessibility research has increased and driven work that centers the

perspectives of disabled people. In general, accessibility research often examines the experiences of disabled people through observations, interviews, interactive design activities, and user studies with the common goal of identifying difficulties, frustrations, and opportunities to relieve access barriers. This can have significant positive impact; however, problem solving does not capture the full relationship between disability and technology.

A decade ago, in a departure from predominant theories of the field, Mankoff et al. formalized the importance of taking up a disability studies lens in accessibility research [45]. Disability studies is a field of critical inquiry that centers the lived experiences of disabled people without value judgements about quality of life, and works to elevate disabled voices. Disability, through this lens, is a socially-constructed system, which comprises people whose bodyminds do not—or are perceived to not—exist and/or behave according to norms [69]. Disability can also be claimed as a powerful sense of identity [43]. This view stands in contrast to an individual model, often called the medical model—a perception that disability is a fully individual, embodied experience that is worth less than nondisabled experience. As such, Mankoff et al. argued to shift accessibility research to include critical disability studies in research [45]. Disability studies has subsequently increased in prominence within the field of accessibility.

However, a gap remains in laying out an agenda for what disability studies-informed accessibility research should be, and crucially, how to better integrate disabled scholars into its knowledge production. Here we explore this by centering the experiences of the disabled people we are closest to—ourselves. In line with growing recognition of first person perspectives by minoritized researchers [13, 38, 52, 74, 88], we center our personal experiences as disabled researchers, users, consumers, technologists, and academics as the object of study from which to synthesize these lessons, using storytelling methods [10, 52, 73, 88]. Specifically, we structure our analysis around personal narratives derived from years of informal discussions and a series of semi-structured interviews between the authors. We offer three core observations:

**Ableism:** prejudice against and erasure of disabled people's perspectives is threaded through accessibility research, often covertly, as well-meaning actions and deep structural discrimination.

**Oversimplification:** In service of scoping, accessibility research often frames disability as discrete and isolated blocks of diagnosis,

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symptom, or impairment. Yet, these categorizations are decontextualized and under questioned.

**Connection:** By focusing on impairment, accessibility research often under values supports, systems of professional, familiar, and caring relationships both among us as disabled people, and with our allies. These connections are key for accessibility research to better recognize and respond to access conflicts and to examine the role technology plays in human and environmental relationships, particularly around disability and ally identity development.

Based on these core observations—ableism, oversimplification, and connection— we encourage accessibility researchers to learn and change with us: (1) we *call for a commitment to recognize and repair ableism*; (2) we *caution against the oversimplification of disability and accessibility research*; (3) and we, again [45], *encourage researchers to take a disability studies perspective, centering the point of view, history and context of disabled people*. Additionally, we recommend researchers engage the following practical challenges: engage with more diverse people, widen the relationships accessibility research examines to include their role in developing disability and ally identity, and bring together accessibility researchers, disability studies scholars, and disability industry entrepreneurs.

## 2 RELATED WORK

According to its professional organization, the Society for Disability Studies (SDS), the field of disability studies is “an interdisciplinary and multidisciplinary examination of the nature, meaning, and consequences of disability.” It foregrounds the lived experiences of disabled people and challenges deficit and corporeal conceptions of disability that place it wholly inside bodyminds, all the while shirking access work onto individual disabled people [68].

In this review, we take disability studies as a starting point for elaborating on aspects of accessibility research important to consider through a critical disability lens, and examples of disability theory construction through accessibility research. While this is not an exhaustive review of the intersection of disability studies and accessibility, the highlighted literature directly informs the lessons we derive from our own experiences. We note that we use “disabled person” to mark our claim to that identity, and “disability” in the singular over “disabilities” to recognize that, while impairments may be multiple, disability may be a shared status [40].

### 2.1 Complexity, Chronic Conditions, and Critical Disability Theory

Research on access technologies (AT) tends to focus on a small number of diagnoses/impairments, primarily blindness, Deafness, mobility, and cognitive impairments. For example, when searching the ASSETS proceedings, of approximately 1500 papers 42% use the word “blind”; 40% use the word “cognitive”; 27% use the word “motor;” 14% used the word “Deaf”. Finally, only 10% of papers in the ASSETS proceedings use the words “chronic OR illness OR invisible.” Yet, disabled experiences rarely fall into these discrete categories, and thus complex disability is a primary subject of disability studies [30]. Critical race and disability studies ask us to burst contemporary vacuums and understand these injustices alongside western eugenic and capitalist histories. These have scientized and legalized the incarceration, sterilization, and murder of minoritized

people including those who are Black, Indigenous, people of color (BIPOC), women, and particularly those living where these identities intersect with disability [17, 19–21, 32, 33, 57, 65, 68, 76, 77, 82]. As such, critical disability studies [48] has learned from feminism [26, 27, 39, 84], queer [39, 47, 64, 65], critical race theory [20, 63], and the disability justice movement [14, 17, 25], to destabilize ongoing obsessions with clear, static, decontextualized conceptions of disability.

As a central example, consider the experiences of people with chronic illness, such as those which are invisible and may co-occur alongside other invisible or visible impairments. It is undeniable that illness may come with egregious symptoms warranting medical care. However, other negative impacts exist from: conflicting information online [46] and prejudice like sexism and racism that lead to medical authorities disbelieving and abusing feminized and racialized “patients” [19, 53]. Writer Suzannah Weiss materialized associated consequences with a viral Twitter thread when she asked people with chronic illness how many doctors it took to get a diagnosis; it took her 17 [83]. As part of this expansion and resistance, scholars of complex disability and intersecting identity facets assert their lived experiences to imagine more open and flexible worlds. For example, queer, feminist disability studies scholar Alison Kafer has gained wide recognition for popularizing the term “crip time” to honor bodies that move at unpredictable speeds [39]. She contrasts this with assumptions that tasks can be completed in predetermined intervals. Similarly, disability Studies scholars Ruth Pinder [54] and Susan Wendell [84] have written their lived experiences with chronic illness and intermittent healing to demonstrate the fallacy of being either “sick” or “fit” [54]. They show how they can at once hold multiple, inseparable identities. This perspective conflicts with many workplace and government service eligibility requirements that diagnoses be clear-cut. We brought this attention to our histories, complexities, and fluidities in our self-study.

### 2.2 Disability Studies and Accessibility Research

Disability theory has gained recognition in accessibility research. This was particularly notable when disabled disability studies scholar and anthropologist Karen Nakamura [50] gave the ASSETS 2019 keynote. To summarize the field’s uptake of disability theory, we overview: (1) in-depth engagements with disabled people toward generative design thinking and (2) disability studies-informed theoretical contributions to accessibility research.

First, a body of work has examined the current practices of particular groups of disabled people, often scoped by impairment labels and culture [28]. This offers new ways of thinking about design and development from disabled perspectives [5, 6, 9, 12, 14, 16, 23, 34–36, 38, 41, 44, 55, 58–60, 74, 75, 79, 80]. While not exhaustive, and often not claiming to be doing disability theory, these examples embody one of disability studies’ important tenets: rooting research in the lived experiences of disabled people. For example, from studying an online community of blind parents to learn their co-reading practices with sighted children, Storer et al. [75] proposed that many technologies from smart speakers to audio and enhanced print books may uniquely benefit from the experimental but long-refined reading practices of blind and sighted co-readers. Storer et al.

positions blind readers as experts whose insights may benefit mainstream technology design, rather than just a group underserved by book production. Similarly, in an echo of disability studies scholar Irving Zola's work [89], Lazar et al. synthesized a critical lens on dementia care and associated design through their ethnography of an assisted living home [41]. They push back on notions of "successful living" and forms of research participation which emphasize completing particular tasks or achieving design goals, and instead take note of all bodily rhythms and behaviors as forms of engagement and communication. This growing literature is an exciting indication that more accessibility researchers consider disabled people as experts in reimagining designs, and moving beyond expectations laden by narrow norms.

The second body of literature concerns disability studies-informed theoretical developments in accessibility and greater HCI research [8, 22, 25, 87]. For brevity and relevance purposes, we focus on the intersection that particularly informs our work—the connection between visibility, disability, and technology. Disability expressions are often negotiated differently depending on factors such as symptoms, perceived risk in disclosing, and what we need from our environments. One consequence of this is that much AT marks people as disabled based on stereotypes [55]. People often use or abandon AT as visible markers of disability while negotiating their self-presentation. For example, since many people are disbelieved when they share symptoms, assistive devices like wheelchairs are sometimes welcome because they legitimize "disabled" behavior. Similarly, stereotyped markers of disability status, such as the symbol denoting accessible parking spaces and restrooms, can help code surveillance technology use as acceptable when accommodating disabled people [22, 55].

While AT use can be beneficial, it can also do harm. Disabled people are regularly and inaccurately coded as unrepresentable, and asked personal questions about their impairments [63], making being invisible enviable. For example, to avoid discrimination, some people keep disability hidden by preferring to use mainstream technologies customized to their needs. They may also use technology to access safe spaces which decenter normed expectations [22, 60]. Finally, some of the worst treatment of disabled people happens when someone appears nondisabled and becomes visibly disabled as they don AT. Examples include acquiring a stored wheelchair after disembarking a vehicle walking [22, 63], or in the reverse case, when a white-cane user is shamed when "caught" using a smartphone because its use is presumed to require vision [71]. Such moments, when practices do not meet expectations, can be missed by research that examines disability as a singular impairment. This growing body of literature, which we expand, demonstrates the importance of the contextualized and embodied lived experiences of disabled people, particularly in moments and places when they violate standardized conceptions of disability.

### 3 REFLEXIVE SELF-STUDY

Our self-study explores themes around our experiences as disabled people and researchers. Traditionally, scientific inquiry creates intentional distance between researcher and subject to increase objectivity. This trade-off carries the implicit assumption that objectivity is possible, and that it uniquely authorizes the knowledge produced.

In accordance with feminist stances [31, 78], our lived experiences have taught us that when studying humans, this assumption is usually wrong. The data lost by not engaging directly with human subjects may compromise the nuanced details that protect us from our own biases. Accordingly, in this paper we position ourselves as both researcher and participant to collect and examine our own experiences with disability. As such, we draw on methodological developments of feminist HCI [7] which is gaining increased attention for foregrounding the lived experiences of both participants and researchers whose identities are under-represented [52, 62, 88].

#### 3.1 Method

This research took place in four stages: (1) informal investigation, (2) reflexive planning, (3) formal data collection, and (4) inductive synthesis. In late 2018, Hofmann and Mankoff began an informal investigation into the role of disability theory in their own research. This was sparked by their lived experiences, which did not fit either the individual or social models of disability. This informal investigation took a number of forms (e.g., seminar discussions, false starts of new research, and countless derailed advising meetings) and included expanding the conversation to others. Specifically, Bennett and Kasnitz were recruited to this work as, respectively, an accessibility expert with a focus on disability studies, and an elder of the field of disability studies and anthropology and long-time collaborator in the effort to bring a disability studies perspective to accessibility research.

Ultimately, not finding traditional HCI methods adequate, we chose the critical inquiry method of duoethnography [51]. Through ongoing dialogue, we reconstructed our understandings of disability, academia, and technology by sharing and reflecting on our disparate experiences and by embracing the recognized methods of autoethnography or duoethnography—the elevation and formalization of ethnography that centers the ethnographer's life as subject (auto) or two ethnographers' as paired mutual subjects (duo).

We co-developed a semi-structured interview, conducted between authors: Hofmann to Bennett and Mankoff; Mankoff to Kasnitz and Hofmann; and Bennett to Hofmann. We recorded our initial interviews and automatically transcribed them for further review. Following these interviews, authors wrote narrative reflections on the discussed topics and events. Each narrative sparked new memories and reflections which were discussed and documented in regular meetings.

As the meeting records, interview transcripts, and personal narratives collected, we began to analyze our experiences and inductively developed a set of themes. During this synthesis stage, additional memories arose and were added to the narrative set. This process was repeated until we reached saturation with respect to jointly developed themes. The themes centered on disability and our own experiences with and theorizations of, technology and accessibility research, guided by our in-depth engagements with critical disability studies.

#### 3.2 Author Disability Biographies

We precede our findings with brief vignettes about our symptoms and social impacts to contextualize the sections that follow. These biographical moments and subsequent narratives include mentions

of self-harm, and abuse by the medical industrial complex; we encourage readers to proceed with care.

**Hofmann, The Fainting Goat:** I am a researcher at Carnegie Mellon University who jokingly identifies as a “fainting goat” because of my unexplained, undocumented, syncope (i.e., fainting) disorder. At 13 years old, I began to faint sometimes randomly and sometimes from audible and olfactory triggers. I adopted the term “fainting goat” after my pediatrician showed me YouTube videos of a particular breed of narcoleptic goats. In addition to the syncope, I have a history of migraines, anxiety, and PTSD which impact my cognition. In 2019, my symptoms worsened into prolonged fatigue, reduced mobility and balance, and acute tremors. Despite seeing medical experts across the United States, I still have no diagnosis or official documentation of my disability.

**Kasnitz, Grounding Disability Studies:** I am the anthropologist in the group. I am a senior organizer, mentor, and advocate for interdisciplinary disability studies and a founder and current Executive Director of the 40 year old Society for Disability Studies. My familial idiopathic generalized torsion dystonia (which looks like Cerebral Palsy) now affects all my voluntary movement and speech but did not appear until I was 9 and is still changing. I have negotiated a curvaceous path through paternalism and proffered brain surgery, contract labor and academic exclusion, to be a feisty 70 year old who speaks my mind, albeit through a human “revoicer.” I am still waiting for the right typing hardware/software solution to get ideas from my brain to others. Mankoff and I seem to meet to discuss disability and technology at least once a decade.

<i>My disability is that when</i>	<i>I can't blend.</i>
<i>I walk into a room,</i>	<i>I can't hang out</i>
<i>Everyone in that room</i>	<i>in the background.</i>
<i>who can see or hear</i>	<i>I'm always visible.</i>
<i>Labels me as disabled,</i>	<i>I'm on display.</i>
<i>And treats me differently.</i>	<i>And of course my reaction is</i>
<i>Because of how I look,</i>	<i>If everyone is going</i>
<i>And how I move.</i>	<i>to stare anyhow....</i>
<i>Because of how I sound,</i>	<i>Let's give them</i>
<i>I am instantly set apart.</i>	<i>something to look at.</i>
<i>And that is my disability.</i>	

**Mankoff, Illness vs Disability:** I first claimed my disability identity as a graduate student dealing with a multi-year chronic condition in 1996. I am now a full professor at the University of Washington, having changed institutions three times since my graduate student days, and acquired a second major chronic illness in 2006. While I am open about my diagnosis and journey [24, 61, 72], my reasons for claiming the disability identity have been driven not by my personal experience of illness, but rather by barriers in access. Illness alone represents an ongoing negotiation with self and physicians, a journey to both acceptance and healing. A disability identity, on the other hand, represents a reason to claim the right of access, a reaction to moments such as not being able to open a door with a broken switch or not being permitted to attend a program committee meeting virtually.

**Bennett, Contrasting Conditions:** I am an accessibility researcher at Apple Inc. and Carnegie Mellon University. A blindness

diagnosis at birth was acquired quickly, but my journey has been characterized by difficult decisions, abuse and judgment over the decades. In my first two years, my parents often faced inaccurate speculations by doctors of my capabilities and they advocated extensively for my right to an education. I had some usable vision until age 16 and I regularly visited specialists who implored acceptance of invasive medical interventions to preserve my remaining vision which I now characterize as abusive. I chose to forgo additional treatments at 13, as I believed I would become totally blind no matter what. Based on narratives I have read by people with similar vision impairments undergoing a similar trajectory of vision loss, I have since discovered my decision was educated and informed despite medical professionals’ dismissing me as irresponsible. Even still, being steeped in worldviews that total blindness is a universally negative experience meant I never talked about my transition to total blindness and accompanying negative mental health symptoms including prolonged depression, harmful ideation, and intense anxiety. The contrast between my blindness and mental health have been particularly stark since my transition into an academic setting, where I have obtained extensive training in nonvisual work and daily task completion, as well as transitioned from being blind but not disabled to proudly disabled, a change I credit my disabled friends for cultivating. Depression and anxiety remain intermittently acute, undiagnosed and poorly treated.

## 4 RESULTS

As described in our methods section, our process of narrative reflection was condensed through iterative discussion into themes. These themes help to highlight our lived experience of disability, as well as the implications of that experience for accessibility research.

### 4.1 Ableism

Ableism, defined by attorney and activist Talila Lewis, is “a system that places value on people’s bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism and capitalism” [42]. Ableism can be internalized, overt, or implicit. Our reflections illustrate how ableism infiltrates our perceptions of ourselves as disabled people, the research we choose to do, and our daily experiences. Revising our own ableism has required us to be vulnerable and pay ongoing attention to our complicity in its perpetuation.

**4.1.1 Internalized Ableism: Accepting Our Own Disability.** Perhaps the most insidious form of ableism is the internalized notion that impairment is inherently negative. At its extreme, it can lead to erasure of the disability experience, or even internalized self-hatred [15]. The arrival of a disability identity is often separate from onset of impairment. Sometimes we arrive at this identity by being recognized as disabled by bystanders. Mankoff describes, “*I was both shocked and upset the first time I was labeled as ‘disabled’ by a stranger who opened a door for me. The automatic door opener was broken and the stranger noted how important it was that these accessibility barriers be fixed for people like me. By using the button, I had labeled myself disabled.*” Now, as a mother, she works to “*inoculate her son against doubters,*” a common negative experience shared by many with chronic illness, by encouraging her son

to develop a disability identity early in her chronic illness experience. Kasnitz additionally skirted the issue of internalized ableism, “I talk about not really coming out as disabled until acquainted with Irv [Irving] Zola as a mentor at age 30. My sister remarked ‘The only person who ever thought you were in a closet was you.’”

Another expression of internalized ableism is the idea that disability has to cross some threshold of difficulty or suffering to count. After arriving at a bar, Hofmann and Bennett took advantage of the casual environment to speak honestly about their shared experiences with disability. Hofmann recalls, “I did not identify as disabled at the time and was uncomfortable claiming the moniker because I felt ‘too able.’ Bennett responded, ‘you’re F\*\*\*ing Disabled!’ At the time it was relieving to have Bennett validate my experience as an authority on disability because she was blind. I now recognize the ableism innate in that line of thinking; I’m disabled whether or not others recognize it. The final authority on my identity is myself.” Both Hofmann and Mankoff have questioned whether they are “too able” to count. Yet a disability identity can help tremendously by giving language to negotiate negatives and assert rights to access, by recognizing the positives the unique perspective offers, by providing community, by legitimizing the use of accessible technologies, and on and on.

**4.1.2 Ableism among Disabled People.** Even as disabled people, we carry prejudice about other disabled people. Bennett reflects, “I hate unsolicited assistance, but when walking with Hofmann I’ll sometimes clutch at her arm whenever I hear a loud sound instead of trusting her expertise in identifying syncope triggers. Even though I expect people to allow me to bump into things, just like I may when they are not there, I still struggle to accept that Hofmann lives in a world full of loud noises, and can direct when and how she would like to receive assistance.” Practicing the anti-ableism we preach is challenging as we, too, are steeped in an ableist society. However, Bennett finds the effort worthwhile; “by working through this memory with Hofmann in writing this paper, I now know to intentionally work on discontinuing that behavior.” The value gained in speaking out about ableism, and learning and correcting it, is something all of the co-authors have experienced.

**4.1.3 Representation: Expecting Disability in Academia.** Another form of ableism that impacts the creation of AT is the assumption that disability is a characteristic of the studied subject. Although disabled academics are increasing in number, and though ASSETS has led the way in cultivating an accessible conference, academia still remains quite inaccessible, and representation of disabled academics decreases with successive ivory tower promotions [17]. For example, though ASSETS is known for long hosting entirely remote peer review, it is a relatively new transition for many ACM conferences. Mankoff recalls: “I have been asking permission to participate remotely at professional events for years. Only as program committee meetings grew too large, and then again when social distancing became necessary during the COVID-19 Pandemic, was this practice broadly adopted, allowing me to finally feel like I could participate as an equal.” Too often, disabled people not expected to occupy positions other than student or research participant, are told that resources are too scarce, or that their individual accommodation might disrupt the needs of the whole. Kasnitz contradicts this with experience organizing SDS and other disability studies events long run by and for disabled scholars. “It is no surprise to me that in March

2020, SDS was able to move a 400 person, 40 session meeting online in just three, exhausting weeks while other conferences were cancelling all around us. We predict that like voice recognition software, our protocols for online access will be widely adopted for everyone.” While others have argued for the importance of improving accessibility at all levels of academia [88], accessible systems and processes currently in place are not yet sufficient. The cultural change must run deeper for such systems and processes to stay centered, and when it does we will benefit with a resilience that improves access not only for those with disability, but also the temporary impairments caused by everything from personal injury to the worldwide changes caused by COVID-19.

Disability culture means not only prioritizing access earlier and more consistently, but also adopting important lessons that go beyond traditional notions of accessibility. These include the values of slowing down despite the constant pressure to do more in academia; balancing personal care with work; time management skills; collaboration skills; resilience; multi-modal communication; and problem solving. Perhaps the most misunderstood among these is time. A disabled person often moves at a different speed (e.g., crip time [39]). Whether working with a disabled colleague or planning a user study with disabled participants, success often demands a willingness to, as Mankoff says, “slow down and focus on quality over quantity.” On the other hand, we note that the right technology can save time. Time is a space where understanding and accessibility play important roles in providing choices rather than making assumptions. Our review of ableism demonstrates the power and necessity of addressing our biases and misconceptions, and the necessity that this take place both in our personal relationships as well as at the structural levels that dictate the far-in-advance planning of conferences and what qualifies one for tenure.

**4.1.4 Segregating Accommodation from Public Space.** Processes to accommodate access needs are often separated from their contexts. Bennett reflected on the discontinuity of official accommodations and reality, “I have never been fully supported in a workplace and I constantly navigate the processes of getting workplace accommodations (whether through official channels or not), as a student, as an instructor, and as a researcher. Yet, this labor remains invisible unless I explicitly call it out to colleagues. Even the most accommodating workplace does not eliminate the need for my colleagues to intentionally work in ways that I can access and the need for us to negotiate which practices will work best for everyone. In fact, the official character of workplace accommodations has at times led me to ignore others’ needs when they don’t fit within those structures since mine are presumed legitimate.” We do not condone nonconsensual disability disclosure, but keeping accommodation separate from other activities creates artificial barriers to including all stakeholders and belies the fact that most accommodations are incompatible with confidentiality. Instead, accommodations are often public and interactional in nature. Kasnitz shared an example of what publicly democratizing access accommodations might look like. “One year, just to make the point, a group of my able bodied colleagues all filled in the anthropology conference accommodation request box with ‘I will need a revoicer when I meet with Devva.’ We modeled how such a brazen culture change allows nondisabled allies to take on some of the responsibility and work involved in creating accommodating group

public spaces.” We recognize that negotiating accommodations publicly often has dire consequences for individuals. But culture change must start with risk. Shared risk will better reflect the interactional nature of all access needs, not just disability, and better serve those whose accommodations are resisted. Nondisabled people and the “out” disabled people like Bennett and Kasnitz who have the privilege of sanctioned disability, have the moral imperative to use their platform to advocate for others’ (such as Mankoff and Hofmann’s) accommodations—their civil rights.

**4.1.5 Bridging Silos and Breaking Molds.** Another form of ableism is the assumption that accessibility research has unique authority despite the existence of another field that explores disability. Disability studies represents a type of knowledge production based on lived experiences that can inform our work, deserves citation, and would benefit from collaborative engagement. This is embodied from an outsider’s perspective on accessibility research. Kasnitz asks, “*can the goals of user centered design be met if it fails to engage with critical theory, disabled scholars, or activists? I cannot say enough. Most disability studies folks don’t have any idea of what accessibility researchers do—not a clue. They have no concept that they themselves could comprehend what you do. There is a presumption, a perception that technologists work on problems that they define out of charity, or to the end of making money off us, not our priorities. We don’t know how to ask technologists the right questions. The process and actual products are too often geared to the most clearly perceived or-defined ‘problem’ (like blindness), or the most dramatic impairments (like quadriplegia), or they speak to everyday minimal impairment. Most of us fall in between. Most technology that I would want is not what’s out there. What’s out there is stuff for children or quads. I need a better way to click a mouse, but not a big neon pink button or a sip and puff switch. By designing for people who do not question you, or whom you don’t question about priorities, your designs cannot break out of established gardens.*” This perspective implores accessibility research to scale back authorial classifications and assumptions to better recognize disabled realities.

## 4.2 Oversimplification

Often when creating AT, we assume a disabled user in an abstract standard disabled mold who can be accommodated to fit into a nondisabled world. The reality of a standard disabled experience, or a standard nondisabled experience, rarely plays out in practice.

**4.2.1 Managing Visibility.** Many accessibility researchers are familiar with the term invisible disability to describe the wide range of impairments that are structurally suppressed or not obviously expressed externally. What is less discussed is how living on a spectrum from total invisibility (i.e. passing) to overt exposure affects how disabled people find their way to a disabled identity and the technologies designed to support them.

When Hofmann declares her disability to justify what she needs, she is often denied since her disability is usually invisible. For example, the lack of a formal diagnosis led her to be discriminated against when requesting rightful accommodations. As a result, she often goes outside the systems designed to support disabled people to get what she needs. For example, “*as an undergraduate, my university would not accept my doctor’s loose diagnosis of ‘Orthostatic*



**Figure 1: Mankoff’s son’s hand crafted cane**

*Syncope Disorder’ (i.e. fainting while standing disorder) as a reason to provide an accessible (air-conditioned) dorm room, even though heat significantly increases the frequency of my syncope episodes. Dorms were primarily assigned by major and Computer Science majors lived in the older Natural Sciences dorm. Computer Engineering students, alternatively, lived in the brand new and accessible Engineering Dorms. Without proof of sufficient need, I went outside the resources set for disabled students, and changed my major, temporarily, to access the accessible living space.”* Despite fought-after and clear requirements that universities offer accessible housing as a reasonable accommodation, the invisibility or imperceptibility of Hofmann’s disability provoked institutional ableism and forced her to solve access barriers for herself. As researchers have noted [22], people with invisible disability and chronic illness may aim to prevent such discrimination by using assistive technologies. But as Mankoff transitioned to not only negotiating her own disability but also to beginning this journey supporting her son, taking up assistive technologies became about more than legitimizing asks for help [9, 56]. “*I’ve worked hard to instill a disability-positive identity in my son. I got her a custom-made, beautiful, engraved cane in her favorite colors ( Figure 1), which has garnered many enthusiastic questions about whether we made it and lots of praise. This cane is a success in my eyes: rather than people looking away/ignoring/ being afraid to say anything, they engage with her.*” Canes present an opportunity to make the invisible visible for many with chronic illness, an opportunity to declare, to accept, and to support rather than to fix [56].

Like Mankoff’s daughter, Hofmann has begun to make her disability visible by using a mobility-cane. Sometimes the cane is necessary to help her balance or to be turned into a one-legged stool, but often it is a tool to tell others when she is fatigued and needs to walk slowly or rest. But making her disability visible can sometimes create new barriers. For example, many public busses lower a ramp for people who the driver thinks cannot manage a step. Often, the bus emits a loud high-pitched alert sound. This can make Hofmann faint, so “*when I approach the bus I have to do this awkward dance of hiding my cane from the approaching bus driver who may kindly assume I can’t take the step, but also clearly reveal it to other passengers who may need to give me an accessible seat.*” In these moments, Hofmann must make her disability both visible and invisible, perceived and ignored.

When a disability is not invisible or hideable, it complicates disabled peoples’ power to negotiate how others accommodate them. For example, Bennett’s status as a blind accessibility researcher cannot be overlooked, sometimes to her detriment: “*I avoid demos and posters at many conferences as I’m often drawn in, whether I’m interested or not, to exhibits that people think may interest me because they are ATs for blind people. Sometimes, I’m asked to share my opinion only to be told that I’m wrong or that I used the demo incorrectly. I know folks are well-intentioned; I understand how rare it is to happen upon someone, outside user studies, whom our technology is meant*

to benefit. But I don't wish to be a spectacle, and so I avoid these events, often costing myself opportunities to see interesting research." Kasnitz offers another example, "because my impairments are visible, I constantly dodge proffered but unneeded accommodations and may never get a chance to ask for what I do need/ want from people who feel rebuffed. A waitress will bring me a paper cup of water that I can neither move nor pick up without crushing. She says, 'now you don't need to worry about breaking a glass.' I say 'Thank You' as I crush the cup with gusto. When offered a half a cup of coffee at a time to avoid spillage, I say 'thanks, make that the top half.' I can drink the top half without picking it up." Because their impairments are not invisible, Kasnitz and Bennett may instead variously perform disability to get what they need or segregate themselves from environments where the perception of that disability is a hindrance.

**4.2.2 Lack of "Proper" Diagnosis.** Being disabled often implies a diagnosis granted by a medical authority. Documentation of impairment and disability in the language of medical institutions is the key to a number of accommodations (e.g., medical treatment, insurance-covered medical devices, and work-place/ school accommodations). But access to documentation is not universal. One of the most insidious of these barriers is the arrogance of the medical system itself. For example, as a child Hofmann "underwent extensive testing but none provided diagnostic results. In response, my pediatrician developed a new theory that my syncope was psychological (either attention seeking or delusional). To my great benefit, my parents disagreed and refused to follow a psychiatric treatment plan. More than a decade later, I've collected my medical records from that time only to find notes on my medical tests that point out 'abnormalities', or are 'inconclusive'. This implies that while the results were not diagnostic, it was also not 'in my head'. To this day most doctors assert that syncope can be the result of 'anxiety' or 'depression', or my personal favorite that 'sometimes young women just faint and I will grow out of it.'" Diagnosis may appear as an objective measure of impairment, but it is granted by a biased system. In Hofmann's case, it was easier for her doctors to assign blame to her psychology, age, and gender, than to accept that their diagnostic methods were insufficient. In any case, the Americans with Disabilities Act does say that diagnosis should not be a barrier to access.

**4.2.3 Different disability: Same Space, Same Time.** We tend to study disability specific to individuals, ensuring their access to a specific technology or space, even for a specific time or task. But we rarely consider how disabled people co-exist. The increasing inclusion of people with disability also increases the likelihood people with a variety of access strategies will share the same space, time, or technology. Sometimes, co-existence creates radical moments of mutual caring by disabled people, even though they are usually portrayed as recipients of assistance [8], which has informed the independent living movement [85]. Recall Hofmann and Bennett's evening at the bar, to which they had walked to with a group of disabled students following a conference reception. Hofmann describes the journey, "Sirens from police cars and the occasional smell of cigarettes and marijuana kept making me faint. We realized that we could accommodate each other's needs. Bennett and another blind student took my arms on either side. I guided them along the streets and they could catch me whenever I went limp." They still use this technique to navigate together.

However, co-existence, perhaps naturally, produces conflicts. Recall that Hofmann hides her mobility cane from bus drivers to prevent them from triggering a ramp and alarm. Bennett, who navigates with a white-cane, cannot hide her cane given its utility. She is similarly recognized as disabled by bus drivers, who trigger the ramp for her. Bennett describes the conclusion of an evening as she and Hofmann exited a variety show of disabled comedians to a nearby bus stop, where they would separate for Bennett to catch a ride home, "since I would board the bus alone, I did not feel comfortable hiding my cane. Hofmann saw my bus pull up before we reached the stop and did not want me to miss it. We could move faster together, with Hofmann as my guide, but we both knew that if the beeping sound began Hofmann might faint. As expected, when the driver noticed my cane, they lowered the bus. Hofmann separated quickly to safely faint on a bench and I rushed to catch the bus. It was a brief and discomfoting goodbye." In one task Hofmann and Bennett's bodies may present opportunities for working together in both concert and conflict. In this case, since Bennett does not need the floor of buses lowered, she will hide her white-cane and walk behind Hofmann if they board together; Hofmann can guide Bennett and the alarm is less likely to blare.

Experiencing and working through these conflicts is legendary. However, negotiating disability is common in disability studies spaces where disabled people are more represented and explicitly included. Kasnitz describes herself "presenting at SDS via Zoom in a meeting of about 30 people. A Deaf woman in the audience wanted everyone to turn off their cameras because of the visual distraction she experiences while watching her ASL interpreters. I had to deny her request because I depend on eye contact with my revoicer and the postural and facial expressions of my audience for feedback as to whether I'm understood... The Deaf woman thanked me for explaining that she was not alone in her reliance on visual communication even if the mode caused conflicts." Disability studies and activist communities have developed a variety of techniques for managing these frictions from which accessibility researchers can learn.

Access is not singularly good or bad, and everyone's access needs vary, complement, and conflict. Technology is not flexible enough to make space for these conflicts; nor does it facilitate the art of thoughtful compromise in access work.

## 4.3 Connection

Interdependence [8, 49, 85] embeds access work in a larger context of relationships, disability identity expression, and shared creation and conceptualizing of disability. A significant, but relatively unexplored, piece of this is the ways in which disabled people and their allies and close companions relate to each other.

**4.3.1 Making Shared Meaning.** While research recognizes the role of professionals and volunteers in the ecosystem of AT [55, 70], our experiences demonstrate the role AT plays in making shared meaning with those close to us. Hofmann tells us making can be, "a moment where a husband declares his role of a caregiver and a person who respects and loves a disabled person. Although my research focuses on the intersection of making and disability, I see no use in making for myself. But my husband seemed to have learned more from reading my papers than I had from writing them. In crafting me a cane (Figure 2) as a wedding present, he expressed how he embraces



**Figure 2: Hofmann’s husband designed and lathed a custom formal cane as a gift for Hofmann to use during their wedding as both an assistive device and a fashion accessory.**

his role as a caregiver even though this violates the gender norms taught by his parents.” While research has examined how making can be a tool for empowerment, we rarely explore how having work done by the right people can be differently empowering. While the gift of a cane from her husband signified his embrace of her identity, accepting the gift of a cane from her mentor, Mankoff, signified self-acceptance: “I was struggling to manage my new impairments amidst the stress of presentations and travel. After years of encouraging me to use a seat-cane, Mankoff finally decided enough was enough. She left her own seat-cane for me to pick up at the hotel lobby. In the moment, this was just problem solving, ensuring I’d get through the conference, but this was the push I needed to begin using my own cane.” The impact of canes continued through storytelling during this self-study. Bennett was ashamed of using a white-cane for several years. Though Bennett’s pride in using one evolved before our conversations, learning of canes’ additional potential to symbolize and deepen caring relationships transformed her personal understanding of support systems. Like all technology, AT exists in a system of relationships. None of the canes in these narratives completely resolve the users’ barriers to mobility, nor offer novelty over standard solutions. However, they exist as tools to work through the meaning of disability in a relationship. Making and curating allows us to express our roles as care-givers, care-receivers, partners, family, mentors, and mentees. The acquisition of AT means more than just the access it brings.

## 5 DISCUSSION

In this section we examine how our described experiences influence our work. We reflect on how research is shaped by ableism, oversimplification, and connection.

### 5.1 Checking in on Covert Ableism

As other research in HCI has pointed out regarding the field’s racism [52], injustice does not merely happen through discrete overt acts. Rather it is threaded through what we do, including our research,

even when well-intended. Disabled people are not exempt from being ableist; we commit injustices to other disabled and marginalized people—even ourselves. We all identify moments when we had to rewrite our ableist assumptions and actions. Bennett did not transfer her experiences being patronized until Hofmann reminded her that she had a lot of experience detecting and responding to syncope triggers. Mankoff reexamined her ideas about disability when she was coded that way, and frequently confronts and learns from moments when she forgets, or fails, to accommodate needs of her disabled students and colleagues. Bennett’s proud claim of disability identity and her ability to be out even in professional environments helped Hofmann expand what life experiences she understood as disabling. Kasnitz has had to learn to not feel put out when asked to give ASL interpreters screen real estate and to respond to the needs of sighted students who struggle to process visual text. We argue that naming ableism is necessary for its revision. Accepting this enables learning and growth to move past debating whether discrete acts are ableist, to revising them.

This action takes many forms: advocating for equitable treatment and access of our disabled colleagues, seeking-out and elevating the perspectives of disabled people in academic spaces (e.g., Deaf and disability studies scholars [13]), and redesigning systems and technology to address ableism instead of impairment. One way to approach this is to take a disability studies perspective, which centers the point of view of the disabled person. This gives a voice to disabled people and will require giving them power as well. Practicing disability studies can amplify questions about control, agency, and responsibility in research and technology design. It can mean designing technology that requests that others change to accommodate disabled people rather than requiring disabled people act more “normal.” Researchers of social accessibility already recognize AT does not operate in a vacuum; bystanders notice and code people, often based on harmful and inaccurate stereotypes [55, 70]. With disability studies, we may expand the territory of accessibility research by identifying that our work must support disabled people’s need to both co-exist with an ableist society (to fit in or be socially acceptable) and to wholly reject that ableism (to demand a new society).

### 5.2 Disability beyond Oversimplified Diagnosis

As we have argued, disability identities are multidimensional and complex. By designing AT one impairment at a time, we may make the problems we need to solve more tractable, but inflexibility may create new ones in the process. AT will be more robust and useful if it can operate in contexts where disabled people are not always recognized as disabled, may have more than one functional impairment, and/or where more than one disabled person exists. Consider Hofmann and Bennett’s example of an accessible ramp on buses. While ramps and cautioning passersby when they are in motion meet a critical need to make public transit accessible to many, they create barriers for Hofmann who, sometimes, cannot take steps, but also cannot access the bus when there is a blaring alarm. What is seen as a universal solution to making public transit accessible, in our case, at once repaired and created inaccessibility.

Further, consider how segregating assistive technologies by diagnostic categories reinforces social structures that disenfranchise



people whose impairments are multiple, undocumented, or otherwise do not fit into these categories. For example, by expecting a particular type of diagnosis, universities can exclude Hofmann from air-conditioned housing and force her to address her access needs through loop-holes. This example also illustrates how decisions of what/who counts as disability/disabled are spaces where oversimplification and bias occur. Hofmann's story shows how structural and individual bias can lead to disbelief and denial of a person's disability experience. The definition of "what counts" is a concern for accessibility researchers as well, and is visible in reviews that question whether something "is an ASSETS paper" as well as the choices we make as a community about what to work on.

There are transformative moments in interactions among disabled people when they realize the diversity, and sometimes conflict, of their collective experiences. Indeed, such moments scaffold disability justice recommendations to hold regular access check-ins and negotiations at events [37, 53]. Supportive communication and compromise may convert conflicts to moments for awareness, growth, and creativity across varied disability experiences. However recasting conflict as opportunity cannot ignore equity. This necessitates positioning power analysis as a process through which to decide how resources are distributed in times of conflict. Recall Bennett's choice to forego autonomous navigation when boarding buses with Hofmann to reduce the chance the driver will lower the ramp and thus activate an alarm. As technologists and researchers, we must be aware of our own power and how it affects and defines these conflicts. It may not be possible to create technology that is universally accessible, but we can consider how our technology enables conflict resolution in-situ. Consider whether a design is flexible and provides resources to disabled people to modify it to meet their needs. Recognizing the inevitability of conflict does not justify inaction; it creates opportunity for innovation.

### 5.3 Connecting Disabled People

Across our stories is the theme of connection. A connection with Kasnitz gave Mankoff the tools to accept and identify as disabled which she passed on to her son and Hofmann. Hofmann and Bennett's interdependence laid the groundwork for disability identity development. Hofmann and Mankoff's connections-through-designing custom canes with their loved ones demonstrate how technology can be a site for cultivating disability positive relationships and transforming technologies from shameful tools into embellishments of pride [56]. These stories not only relayed connections important to us, their retelling also strengthened the connections we have with each other and our disability identities. As such, we recommend storytelling as a critical method of inquiry in accessibility research, as others have [10, 52]. Often, methods for studying disabled people and technology isolate a particular context (e.g., a use case of a new technology, identification of specific access barriers). These specific contexts enable design refinements necessary for accessible design responsive to individual, unique needs. However, these methods often foreclose opportunities to understand how individuals connect. Such interactions, which may come out in storytelling, may represent moments of negotiating conflicts and personal growth generative for both AT design and for

reworking ableism related to the way we approach the connections made toward advancing accessibility research.

## 6 OPPORTUNITIES FOR ACCESSIBILITY AND DISABILITY STUDIES

With our insights, we identify opportunities to combine the expertise of disability studies and accessibility research.

### 6.1 Diversify Populations of Interest

When we examine disability beyond categories of impairments, it forces us to investigate different ways of engaging with disabled people. One highly effective method is to engage with activist/culturally disabled communities led by and in the service of disabled people which often bring together people with a diversity of experiences [4, 18]. For example, Bennett recruits from and frequents cross-disability spaces which center those who are also queer, transgender, and/or BIPOC. However, the gift of diverse participation takes rapport. Access to these spaces requires prior engagement through event attendance, donations of time and resources, and authentic friendships. This engagement must be in the service of these communities, and not exclusively study recruitment. Indeed, as Bennett avoids people who pull her in for feedback she has not consented to provide, requests made in spaces which decenter predominant perspectives (academic, white, nondisabled, masculine) must be preceded with much listening and learning. A productive first step can consist of not excluding participants based on having multiple impairments, and thoroughly inquiring self-reports of demographics as others have recommended [66, 67]. As we believe our narratives as women with multiple disabilities have begun to demonstrate, disabled participants/ collaborators who live at the intersections of oppressions—both by having multiple impairments and multiple marginalized identities—may help us anticipate complexity and conflict and design for its negotiation [57, 67].

### 6.2 Building Disability Positive Allyship

Often, accessibility research concerning relationships among disabled and nondisabled people aims to minimize or eliminate caregiving altogether. While caregiving remains an under-compensated, exploited labor plagued by ample injustices including racism, sexism, and xenophobia [53], a narrow focus by accessibility research to decrease its necessity frames disability as a burden on a relationship and negates a long tradition of research and policy development about self-directed formal and informal personal assistance services [29]. Our narratives demonstrate that relationships for both the disabled and nondisabled people involved can be powerful and positive [8, 11, 53]. When designing technologies that are situated in these caregiver relationships, a disability studies perspective can help us to ask questions about the value of particular care activities. Of course, human help, often skilled, is essential for some disabled people, and technology may play a role in easing taxing aspects of this labor. But certain activities, like those which help to cultivate pride in formal and informal caregivers and personal assistance could also be amplified with accessibility research. For example, both Hofmann's husband and Mankoff found joy and pride in the work of making and selecting a cane for disabled people they love. In this case, making as empowerment research is lost on Hofmann

who does not need to be empowered to make; she does so regularly as part of her career. But making became an essential method for her husband to develop and demonstrate his ally identity. Widening accessibility research to espouse disability positivity more generally and strengthen allyship, as our stories show, will ultimately support the field's mission to increase access.

### 6.3 Alliances with Disability Studies

Finally, we recommend that accessibility researchers strengthen alliances with disability studies scholars. Whereas we have seen an uptick in the ways disability studies is recognized as a crucial lens for technology design [50], we push further toward meaningful and ongoing reciprocal relationships. Recall Kasnitz's concern that she and other disability studies scholars fear they know too little to reach out to accessibility researchers. Yet, among other things, we can learn from their long history of anticipating access needs and working out conflicts publicly and in-the-moment. As such, we conclude our discussion with recommendations based on reflections on Bennett becoming an unofficial disability studies scholar.

Departments should allow, encourage, and even expect new accessibility researchers to take disability studies coursework. Including disability studies in in-department curricula is an essential first step. Committing to the study through dedicated coursework often gives students much deeper dives into disability studies without the pressure to immediately connect their learning to solving design problems, as Mankoff et al. [45] recommended. Where graduate courses do not exist, Bennett has organized independent studies with disability studies faculty. Whether or not dedicated disability studies programs exist, disability studies learners will find relevant courses in many departments like English, American studies, anthropology, gender and ethnic studies, many taught online, or with self-study syllabi (e.g., Black Disabled Women [81]), and many useful resources by following relevant collectives on social media such as the Teaching and Learning Critical Disability Studies group on Facebook [3], and by joining the Society for Disability Studies (SDS) [68]. Though coursework can offer dedicated instruction, ongoing attention to burgeoning interests in disability studies will cultivate stronger relationships with the field. Finally, SDS hosts conferences with fees lower than ACM events and which support alternative and accessible forms of participation. SDS conferences offer multiple submission types, most of which promote discussion and are peer-reviewed as abstracts for future full papers.

At a structural level, in addition to requiring conference publications for tenure cases, we argue for the relevance of disability studies work to a professional portfolio. If your institution enjoys more resources than many humanities departments, recruit disability studies-oriented speakers and extend attendance invitations to disability studies-focused scholars and their communities. Similarly, ASSETS and other conferences featuring accessibility research might co-organize sponsored workshops and other forms of participation that explicitly draw together disability studies scholars and accessibility researchers like recent efforts by organizations including ASSETS [2] the AI Now Institute, Microsoft Research [86], and IBM [1]. We note that infusing workshops into our programming is not new; rather, we recognize these organizations as examples for their efforts to invite disability studies scholars and

people with disability, and to offset costs to allow for attendance by people whose affiliations cannot sponsor them. We believe that citing disability studies research in our papers is an important but only a beginning step toward future, stronger alliances among our communities. Though the specificity of these recommendations may change, we argue that the types of involvement they symbolize may lead toward shared language and mutually-beneficial relationships among accessibility and disability scholars that could ripple into entrepreneurial and policy worlds.

## 7 CONCLUSION

Whereas the field of HCI has been built on recognizing and designing for contexts, we draw attention to the ways contexts connect, and even conflict. In this paper we study these influences in our own experiences of disability. By situating ourselves as both the observer and subject of this analysis we are able to access the connections between specific moments and contexts and elevate the expertise we gain by being disabled.

From our narrated experiences, we exemplify how disability is often mired in ableism and oversimplified. We reflect that one consequence of these reductions is that disability is often abstracted to static and discrete categories of impairments which ignore how disabled people: fluidly transition from states of visibility and invisibility, are not their medical documentation (if they even have any), and co-exist together despite conflicting needs. Such pitfalls perpetuate the development of technology which fail to consider what access conflicts may arise when deployed, especially in company with different disability experiences. In contrast, technology shaped by disability-positive, human connections which embrace the complexity of plural disability identities, can address novel spaces for design and help to elevate people, with their complexity, rather than force them to collapse for categories' convenience.

Based on these findings we call on accessibility researchers to (1) commit to recognizing and repairing ableism; (2) study disability beyond diagnosis; (3) incorporate a disability studies perspective that centers disabled voices and gives disabled people agency and control; and (4) incorporate reflexive, interpretivist study as a regular and essential practice toward portraying disabled people and to guide thoughtful technology integrations with real life goals. Toward these ends, we identified three first steps: to diversify the populations we engage, to widen the types of relationships we examine to encapsulate how disabled people and allies develop their identities together, and to continue building bridges with disability studies communities. We believe that by intentionally holding complexity as our constant, we may anticipate and recognize a richer diversity of people who can help question what we take for granted in our work and who are already reimagining accessibility.

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