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JUSTICE AND EQUITY-BASED APPROACHES FOR TECHNOLOGY DESIGN WITH DISABLED COMMUNITIES

A dissertation submitted in partial satisfaction
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

COMPUTATIONAL MEDIA

by

Leya Breanna Baltaxe-Admony

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Abstract

Justice and Equity-Based Approaches for Technology Design with Disabled Communities

by

Leya Breanna Baltaxe-Admony

Despite good intentions for disabled communities, research and design products and processes often lead to unintended harm and negative effects. Like sexism and racism, ableism is woven throughout our technological, cultural, and social ecosystems by default [7–10]. Engineers and designers working in the space of accessibility and assistive technology want to do good and improve the lives of others. However, without addressing systemic ableism and its intersection with race, gender, economic status, etc. we risk harm surfacing through our designed worlds and processes. Traditional technology development and human-computer interaction practices do not provide the tools to consider systemic issues. To understand what practices of resistance and liberation look like in the context of technology and disability, this dissertation looks at how social justice orientations change the day-to-day work of researchers and designers.

To explore this area, this dissertation includes a systematic literature review of social justice in HCI, semi-structured interviews with those interested in disability justice and technology, and the development of a novel method that carries values found in the literature review and interviews. Through the results of these studies, this dissertation provides actionable practices for future technologists seeking to bring just and equitable practices into their work.

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A major thank you to the Sins Invalid Collective, the Disability Culture Club, and Disability Visibility Project for their cultural work and advocacy. Thank you to those who were part of discords, book clubs and community discussions with me that continue to help shape my outlook. Thank you to UAW 2865.

This work was undertaken in unsteady times. There are countless people I have to thank for their inspiration, support, and camaraderie. I could not have come this far without finding a community.

Chapter 1

Introduction

> *"We must, however, move beyond access by itself. We cannot allow the liberation of disabled people to be boiled down to logistics. We must understand and practice an accessibility that moves us closer to justice, not just inclusion or diversity."*
>
> – Mia Mingus, writer, educator, transformative and disability justice trainer [11]

The Human Computer Interaction (HCI) community has recently seen a growing emphasis on social justice. In the last two years alone, we've seen subcommittees, events, and keynotes on social justice and identity-related topics within key conferences. This emphasis is evidenced by an increase in the number of papers and workshops on issues related to identity, care, and justice ranging across feminism, disability studies, critical race theory, queer theory, and more (see [12–20]). In this work I explore disability justice (DJ) in HCI. I begin by looking at how justice is approached overall in HCI research contexts before narrowing in on practices related specifically to disability justice. Although strongly interrelated with others, disability justice is a unique subdomain of thought, activism, and community. Among the myriad potential focuses for social justice in HCI, I've chosen DJ as a topic for my dissertation because of my relationship to disability, care work and my ongoing work as an accessibility researcher.

Concepts of identity, justice, and equity are relevant to technology in the same way they are essential to our lives. Technology pervades our everyday lives and is now more than ever the medium through which we communicate and relate to one another. Technologies can unintentionally hold personal and societal biases [7, 21]. Scholars have increasingly sounded the alarm for what happens when technologists do not consider the social and ethical implications of their work in fields of HCI, accessibility [22, 23], machine learning [23], robotics [24], and more - concerning race [21], gender[25], ability [26], sexuality [27], socioeconomic status [28], carceral status [29], and more [7, 30].

There are no universally agreed upon socially just approaches, outcomes, topic areas, practices, or methods of engagement. That can make engaging with topics of identity and critical studies tough for some [31]. The possibility space holds multitudes, and not all who work toward social justice label their academic endeavors as such. I seek to uncover methods and strategies that HCI practitioners use based on disability justice ideologies, as well as their personal journeys to using justice-oriented practices in HCI [*]. In my work, I seek to understand, illuminate, and build on ongoing justice-related practices in HCI and accessibility research.

Justice is a relatively new subject coming up in the realm of HCI (See Figure

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[*] This inquiry is specific to research, but it should be noted that DJ activists have made resources around practices that technologists would look to. For example, the ''Access is Love Reading List" [32], ''26 Ways to be in the struggle beyond the streets" [33], and the ''Black Disability Justice Syllabus" [34]

2.2). Unfortunately, the pursuit of justice is anything but new. Disability is only one axis of our collective liberation but an essential one. DJ emphasizes ‘’cross-movement solidarity” and ‘’collective liberation” [4]. In the words of an aboriginal activists group:

> *“If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together.”* – Aboriginal activists group, Queensland, 1970s

I hope to use this academic work and my position as a researcher to contribute a drop to the pool of our collective liberation. The technology researchers, engineers, and designers who are the audience for this work hold the power to create our technological worlds and futures. It is my hope that improving our collective understandings of justice and technology will help us to avoid and eliminate barriers within them, and *‘’move beyond access to wholeness.‘’ - Mia Mingus* [11]

In this introductory chapter I discuss my research space and questions as to this dissertation’s significance. Next, I cover important terms. I then motivate this work by problematizing commonly held beliefs about technology and disability. I include an abbreviated history of assistive technology (AT), and look to the future - what we stand to gain by honoring/heeding the advice and wisdom of disability activists and scholars. Through this introduction I provide context for why technology and its development are social issues in need of a justice orientation.

1.1 Research Space and Questions

The research space I explore herein is one that would be difficult to measure within one dissertation research agenda alone:

- *How can justice and equity-based frameworks transform the practices and outcomes of technologists who engage with disabled communities?*

It will take the efforts of many individuals. It is a question I hope we continuously work towards answering. While I'm disappointed that we have yet to establish justice as a baseline, I am not the first and will not be the last to consider these issues. I am hopeful and excited for many more creative practices to come. This overarching question is also a proclamation: things CAN be transformed. Just practices are possible and are continuously emerging.

My dissertation is guided by two smaller research questions:

- ★ RQ1: What are common practices for technologists who do justice and equity-based work?
- ★ RQ2: How do we teach these practices to HCI practitioners new to the space of disability and access?

My overall goals for this research agenda have been to understand the practices of those who do equity and justice-based work within and outside of technology contexts. Then, to illuminate existing or develop new methods for onboarding technology researchers into thinking more deeply about disability and disability culture.

1.2 Significance of Dissertation

RQ1 requires gathering information on practices used. RQ2 requires establishing pathways to teaching them. Together, the broader significance of the study includes the following [*]:

Phenomenon: This dissertation helps to establish clear pathways for technology researchers to begin equity and justice oriented work within disability communities. Knowledge surrounding daily justice oriented journeys and practices and questions otherwise comes from extracurricular exploration or mentorship.

Discipline: Involving concepts of culture and identity has been criticized for the potential to scare newcomers away from assistive technology work more broadly. The work herein contributes to critical and justice related literature in the SIGACCESS community by bridging activism and human centered design practices as clear, actionable strategies.

World: This has the potential to help future researches make real world impact by changing what work is emphasized and how it is taken on.

1.3 Terms

This section covers terms readers may find throughout this document.

- **Ableism**: Prejudice, discrimination, and exclusion of disabled individuals who are seen as in need of changing in order to navigate society as expected [9, 36]. See: ‘’Ableism is The Bane of My Motherfuckin’ Existence”[36].

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[*] This section follows the significance format recommended within [35]

- **Accessibility Research in HCI**: Uncovers or aids in digital and physical access issues, while assistive technologies are artifacts that facilitate that access. I use accessibility research to mean that within HCI. See Mack et al.'s review of accessibility - ''What do we Mean by Accessibility Research." [37]

- **Assistive technology**: Defined in US law as: *''Any item, piece of equipment or product system, whether acquired commercially, off-the-shelf, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities."* [38]. It is used to maintain or improve access to education, vocation, and society more broadly. Examples of non-computational assistive technologies are wheelchairs, prosthetics, stimming toys, and white canes. Computational/computationally mediated assistive technologies include closed captioning, speech-to-text services, wayfinding apps, and computerized prosthetics.

- **Design Saviorism**: Often occurs when well-meaning technologists want to apply a new advancement to do good in the world. It is the view that as designers we can and should rescue or fix what we view as the problems of marginalized communities [39]. Seeing the work we do in assistive technology as charity [40] and profiting off of it. See white saviorism, and voluntourism. Also related to Technosolutionism [41, 42] where tech innovation is seen as capable of solving all issues - even ones that already have solutions, would be better solved without technology, or dont exist at all. Both terms are common in the space of disability because societal internalized ableism positions disability as a problem to be avoided or fixed.

- **Disability**: Used herein to collectively indicate anyone who may face ableism or societal isolation by virtue of just being. This includes *''physical impairments, people who are sick or chronically ill, psych survivors and people with mental health disabilities, neurodiverse people, people with intellectual or developmental disabilities, Deaf people, Blind people, people with environmental injuries and chemical sensitivities, and all others who experience ableism and isolation that undermines our collective liberation"* [4]. However, disability is not a word that all identify with, and one that can be difficult/unhelpful to claim for some. There are many reasons individuals may not identify as disabled or use that language. It may be because they feel that it is not an accurate description of themselves; being turned away from medical care; because of internal and external ableism; because they are undiagnosed; or because adding one more label might just be too much [43–45]. All of these reasons and more are valid. I want to highlight the possible discordance of my use of the word with those experiences.

- **Disability Justice**: a movement started by Patty Berne & Sins Invalid to recognize aspects of being that were not served by the disability rights movement. Read Sins Invalid principles of disability justice, and the disability justice primer: "Skin Tooth and Bone" [4, 6]

1.4 Not Just Tech: Problematizing Common Views of Assistive Technology

Despite good intentions for disabled communities, research and design products and processes often lead to unintended harm and negative effects for these communities. Like sexism and racism, ableism is woven throughout our technological, cultural, and social ecosystems by default [7–10][*]. Internalized ableism is a given: a lens through which we as individuals view the world. Engineers and designers want to do good and improve the lives of others. However, without addressing internalized ableism, we risk harm surfacing through our designed worlds and processes. Individual researchers are not at fault, as society tells us that disability is something to pity, solve, and overcome. However, individuals should be accountable for addressing it within themselves. Likewise, when viewed as a design problem, disability is something to pity, solve, and overcome: to help the helpless [46]. We have seen that technologists in accessibility and assistive technology often take this design saviorist or technosolutionist position [39, 41], attempting to solve unfounded problems [47, 48], and creating the potential for harm along the way. These harms can include epistemic violence [49], forced intimacy [50], and outright exclusion [51]. Overall, our design processes extend harms already occurring in our social systems [52] [**]. This section highlights four commonly held views of assistive technology.

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[*] Likewise, these issues compound for people with disabilities

[**] the paragraph ending here was written collectively by myself, Tessa Eagle, and Kevin Weatherwax as the introduction to a primer on avoiding design pitfalls when working with disabled populations. The primer in full is not yet publically available

1.4.1 Viewed as A-political, A-social

For many, assistive technologies are a part of the experience of living with a disability. These technologies will always be tied up in social perception and culture. Assistive technologies can cause stigma by outing people as disabled [53], and the decision to use AT can be complicated by stigma and personal grief [44,54]. As Alison Kafer, feminist studies scholar, puts it: *Neither assistive technologies nor our uses of them are ahistorical or apolitical* [55].

1.4.2 Viewed as a given

The ability and inability to opt out of technology use is a concern for many, regardless of ability. Reasons someone might want to opt-out include privacy concerns [56,57], values-based decisions [58], or just wanting to unplug [59]. For example, one may choose not to put their photo online due to privacy concerns. Yet for people using computer vision based AT to gain visual access, they must share camera access with little transparency into their data usage [57]. An access need as simple as needing an uber driver to find them instead of approaching the car will require an uploaded photo. This is one example of forced intimacy [50,57]. The decision to opt in or out is highly individual, cultural, and political.

These issues extend beyond privacy and into bodily autonomy. The Deaf community holds their own culture including values, language, and practices. At the same time, cochlear implant procedures are commonly medically recommended to children and adults who are deaf or hard of hearing. As Ted Suppalla, a deaf linguistics professor puts it: *I never saw myself as deficient ever. The medical* *community was not able to see that we could possibly see ourselves as perfectly fine and normal just living our lives.* [60] This is an area of particular impact on children who are d/Deaf when parents are pressured to opt in or out of medical procedures on behalf of their children.

1.4.3 Viewed as glamorous

Adaptive technology users in popular media (often called cyborgs) are usually portrayed as ‘’superhumans.” This portrayal tends to leave real disabled experiences out while, simultaneously, being used to project otherness onto assistive technology users [55]. Few DJ practitioners take on cyborg as an identity (see Jillian Weise [61] and Rua M. Williams [62]). The concept of the cyborg is present in core texts of disability studies (i.e., the chapter The Cyborg and the Crip in Alex Kafers ‘’Feminist, Queer, Crip” [55]). For Weise, cyborgism is a way to reclaim the word in either case [61, 63–65], but acknowledges some of the term’s shortcomings. As Weise puts it: *“I feel like it is an impossible task to define myself against the cyborg wreckage of the last century while placing myself in the present and projecting forward. I worry that the cyborg is sometimes just a sexy way to say, ‘Please care about the disabled,’ and why should I have to say that?”*

1.4.4 Viewed as a Fix

Assistive Technologies are often presented as solutions and healers. This always positive framing *ignores the fact that, for many people, adaptive technologies can be painful; the same brace that makes it easier to walk can cause skin breakdown* *or other difficulties*[55].

Assistive technologies take work. There is a labor cost associated with using any assistive technology as described by many disabled writers (e.g., Forlano [26] or Weise [61, 64, 65]). For example, Forlano, a professor of design who sometimes writes about her experience with type one diabetes, must frequently remove herself from meetings and gets woken up in order to recalibrate her automatic insulin pump [26]. Weise is required to stay within a 10lb weight range to maintain the functionality of a computerized prosthetic. There are sensors in the leg that track her weight. In addition to weight tracking, Weise must walk enough each day to justify the expense of the leg to insurance [64].

Technologists often try to offer solutions to fix problems they believe people with disabilities face [41, 66]. Liz Jackson calls this a *"disability dongle."* Jackson defines this as *an elegant and well-intended, but ultimately useless solution to a problem people with disabilities never knew they had* [48]. It is not uncommon to use disabled people as engineering or design problems (i.e. at hackathons) without properly understanding their needs [67]. This frames people with disabilities as inherently lacking [68].

1.5 Accessibility Research: An Evolving History

In the last case, Section 1.4.4, research surrounding technology and disabled populations has focused on how to make the person fit better into society. This is reflective of the medical model of disability. The medical model centers disability on the body/mind of the individual. The medical model has been the general publics dominant framing of disability and people with disabilities [55]. There are many other models [69, 70]. The social model is commonly discussed and centers the disability instead on societally created barriers such as social understandings and architectural barriers [70]. Historically, AT has followed the medical model, helping disabled body/minds to adapt to societal expectations rather than the opposite.

Early developments in assistive technology can be traced back to the rehabilitation and employment of World War I veterans [71, 72]. Federally funded efforts gave way to the development of assistive technologies such as the 1947 Hoover Long Cane (a white cane and technique used for mobility) which was developed for veterans who had become blind during their service [73]. In 1948 amendments to the act allowed the program Vocational Rehabilitation (now known as Veteran Readiness and Employment) [74] to pay for enabling equipment (wheelchairs, hearing aids, etc.) and surgeries [75]. 1954 amendments to the act put government funding towards disability-related research. These funding opportunities still exist today.

The history of AT, as rooted in wartime policy, has had a lasting impact. For example, our field continues to focus largely on injury-related and visible disabilities. As shown in the systematic review of the field, accessibility research focuses heavily on people with physical disabilities (69% of papers), especially those who are blind or have low vision (43.5%). Fewer (27.8%) relate to those with cognitive and psycho-social disabilities. Only 8.9% aim to support older adults. Less than 1% address multiple disabilities [37]. Additionally, separate (insurance and veterans affairs (VA)) funding supports the purchase of assistive technologies versus other devices developed within HCI research, which along with small user bases, drives up the cost. The WHO estimates that only 1/10 people who would benefit from assistive technologies have access due to *''a lack of financing, availability, awareness, trained personnel and high costs"*[76]. Further, baked into much of the work we do is seeking independence and vocational rehabilitation for disabled people. This highlights the fields emphasis on productivity - helping disabled people means helping them produce value.

There is still a mindset that disabled people won't be the researchers themselves, and systems such as design processes and education maintain barriers to access due to this outlook [77, 78]. Scholars across disciplines have raised the issue of academic research and higher education being inaccessible and actively hostile toward would-be disabled researchers and scholars [8, 49, 63, 77, 79, 80, 80, 81]. The focus on productivity has been shifting but has been slower to do so based on the roots of assistive technology development in post-war employment.

Recently, there has been a shift toward critical disability theory. Critical lenses have not been a part of accessibility research by default, but they are slowly making an appearance. In 2010, Mankoff et al. argued for disability studies as a potential source of critical inquiry for assistive technology design in their 2010 paper [46], which was published at ASSETS, the premier conference for accessibility and assistive technology. Through several case studies, Mankoff et al. show that engineers and designers could incorporate meaningful functionality by critically examining the social and cultural experiences of people with disabilities as part of the design process. It was not until 2019 that critical disability studies was brought up again in ASSETS publications [82]. Since then, there has been a growing body of work published that does [49, 54, 83, 84], and I believe critical lenses in this space will slowly become the norm.

Incorporating a critical disability studies lens is one step forward toward centering the lived experiences of people with disabilities in our work. But really, centering disabled lived experiences should be the bare minimum. Disability justice is a community-based activist movement that goes beyond critical study. Taking it on as a lens would require actively organizing towards disabled liberation.

1.6 How Assistive Technology Research Might Change with Views from Disabled Activists

The goals of assistive technology have always been to help enable people with disabilities. Calls for justice are a clear lens into the experiences and needs of people with disabilities. Adjusting the goals of assistive technology to address these concepts could radically change the types of technologies that we develop. In this section, I highlight several ideas from disabled activists that emphasize how taking disabled activists seriously could help us move *beyond access* [11] and into technologies for connecting with one another (Crip Duola, Elders, Community, Access Intimacy, Interdependence), better understanding ourselves (Loss, Grief, Rebirth, Nostalgia), accentuating our unique abilities (Crip emotional intelligence, crip time, disabled joy), and more. These goals can be manifested in both the design process and outcomes of technologists' work.

1.6.1 Crip Emotional Intelligence / Criptiques, Disabled Joy

As seen above, Assistive Technology development offers assistance in learning vocational, social, or mobility skills. It does not generally frame disabled people as having their own skills that we could learn from. People with disabilities, of course, have skills to share, and have some skills just by the nature of experiencing a disability. Crip Emotional Intelligence and Criptiques are defined by Leah Lakshmi Piepzna-Samarasinha to be emotional techniques and skills that are culturally specific to people with disabilities. For a detailed list of these observed techniques see [85]. She says: *Able-bodied people are shameless about really not getting it that disabled people could know things that the abled dont. That we have our own cultures and histories and skills. That there might be something that they could learn from us.*

Assistive technologies could help to accentuate these skills, instead of training or making up for others. For example, one criptique is *noticing and showing respect for all the ways we push ourselves past our spoons all the time.* Spoons refer to spoon theory, which is a system to help describe the energy/pain tolerance one has for a day. Actions all cost a certain number of spoons. You start the day with a set number of spoons and try not to run out by the end of the day. A chronically ill person may be acutely aware of their energy/spoons and choose not to engage in certain activities to maintain energy or to do them differently (i.e, sitting down to do dishes). For example, if I can only look at a screen for a short time today, I could use my spoons for work but I can't play games online with friends later. No assistive technology that I have found utilizes the concept of spoons. Spoons are an intimate way to know yourself and what you are capable of and recognizing when you go too far. One could imagine an assistive technology to help you track, reflect, and celebrate your own spoons.

Celebration is another underexplored concept in assistive technology. Sunder et al. position concepts of joy and happiness as holding an important space in the experience of disability [86]. Assistive technologies do not often explore joy for joys sake, but one area of research in access that excites me is games and play. Researchers have explored the use of Minecraft as a virtual community hub for youth with autism (‘’Autcraft”) [87], and technologically mediated opportunities for playfulness in day-to-day life [88]. As journalist Keah Brown puts it: *My joy is my freedom it allows me to live my life as I see fit.* [89]. Technologists might consider how assistive technology usage can bring joy, silliness, individuality, and leisure rather than productivity and independence alone.

1.6.2 Loss, Grief, Rebirth, Nostalgia

Living with a disability and developing a disabled identity can be an intricate emotional experience. Some pieces of this process may include loss, grief, rebirth, and nostalgia. None of these experiences are necessarily linear and may reoccur as disabilities change throughout your life. People who develop a disability later in life or who are late diagnosed may experience a process of rebirth and longing [53, 55, 85].

Work has been done in technologically mediated reflection [90] but not yet applied in disability contexts (as far as I can tell). Designers may consider how technologies might fit into the narrative of loss and rebirth. Using new methods of being via assistive technology can be scary for someone who has developed a disability, and it might also be liberating. It might be all of those things at the same time. More consideration is needed for how assistive technology fits into that narrative of loss, grief, and becoming. One such article that engages with social aspects of AT use is [91]. Technologies might even assist in self-acceptance and learning new ways of being rather than independence and vocation.

Stacey Milburn and Leah Lakshmi Piepzna-Samarasinha define the ''Crip Doula" as someone who helps others through the stages of being and coming into disability. The Crip Doula is *the more seasoned disabled person who comes and sits with your new crip self and lets you know the hacks you might need, holds space for your feelings, and share* [85]. Community can be an important part of coming into a new way of being. This may be an area that technology could explore. Individuals might not already be a part of a community and may not be able to find (or know to find) a Crip Doula. Technology-mediated mentorship is established within HCI [92, 93], but has not yet been applied to disability mentorship.

1.6.3 Radical Visibility, Identity, Presentation

Some disabilities are visible, and some are invisible (to the untrained eye). Assistive technologies can be visible markers of disability. Being coded by others as disabled or not has social connotations that are situationally dependent. Being ''out" may expose one to stigma or unwanted attention. However, sometimes it might actually be helpful to intentionally present as disabled. One example is getting medical concerns to be taken seriously because disabled people are often not believed. Terry Gallaway presents as ‘’more disabled” by wearing big smudged glasses and looking intentionally less put-together when going into the doctor to get hearing aids [54, 94]. An example of an assistive technology (a cane) unsafely outing someone as disabled is presented in ‘’Living Disability Theory: Reflections on Access, Research, and Design” [40]. Hofman hides her cane as busses approach to avoid them lowering and beeping when the bus driver codes her as having a disability. The sound of lowering and beeping might otherwise cause her to faint.

The concept of visibility is becoming more widely discussed within assistive technology [54]. Assistive technologies might consider social presentation as a primary design specification in their work. For example, most devices are medical-looking: wearables often come in only one shade of ‘’nude” [95]. For hardware technology, anecdotally, it seems to only come in black, white, or silver. Many people with various assistive technologies personalize their tech [96]. This can be another way to explore presentation to support personal identity presentations. Clothing brands like [97] specifically aim to make cool, fitting, comfortable clothing for all kinds of bodies and textural needs. One of their aims is to be radically visible, with loud colors, patterns, and designs.

1.6.4 Access Labor, Informant Fatigue, Forced Intimacy

Designing effective assistive technologies requires working closely with people with disabilities to get to know and understand their specific needs. However, this work takes work! A danger of iterative processes, such as participatory design, is how much work we ask of participants who we are trying to help and how these systems mirror systems already failing them within their communities/cities/states.

Dourish discusses this and other issues in his recent work ‘’On Being Iterated: The Affective Demands of Design Participation” [52].

Access labor refers to the work that people with disabilities are required to do in order to have their access needs met [37,85,98]. These include concerns such as informant fatigue (e.g., being asked too often to share repeated personal details [91]) and ‘forced intimacy’ (e.g., being required to divulge deeply private information in order to gain access [50]). The labor of being disabled may also mean maintaining friendly relationships with caregivers [99], requesting specific accommodations from event leaders, or the everyday work of living with a disability in an ableist world [100]. Disabled Femmes are often asked to do more emotional and care labor than anyone else [85].

Assistive technologists can directly acknowledge the labor required by people with disabilities in both the process of designing and living with existing assistive and accessible technologies (see Section 1.4.4). In choosing methods that center contributors with disabilities, labor should be carefully considered. We can do this by choosing methods that honor disabled work that has already been done [101], paying fairly [30], attributing recognition fairly [98], educating ourselves before interacting with the population and considering what information might be too intimate to ask or publish. Technologies can also take labor into account by considering the required maintenance as part of the design requirements.

1.6.5 Interdependence, Access Intimacy, and Care

Access intimacy, as defined by disability justice practitioner Mia Mingus, is the feeling of being in a space with another person where your access needs are met by default [102, 103]. Interdependence is a concept from disability justice that pushes back on the concept of independence, and independence as a goal. In reality, we all exist within webs of support, giving and receiving help from others. What I love about this framing is that it sheds light on our need to support one another, not just to be supported. An inherent concept in assistive technologies is the frame that people with disabilities are in need of help. The technologies we build do seek to support people with disabilities, but how could we shift to a mindset that enables disabled individuals to be carers, to be cared for, to take part in webs of care? Interdependence has already become present in assistive technology. Bennet et. Al have positioned interdependence as a framework for accessibility research in their 2019 paper. This is an existing example of taking a concept from disability studies and weaving it critically and actionably into assistive technology futures.

Interdependence, access intimacy and care are each interpersonal concepts. They allow us to consider the communities we focus on as social and interconnected. Assistive technologies often focus on individuals, not communities. And if they do, it tends to be on homogeneous communities. Its also important to consider people with various disabilities and the ways they might support each other in shared spaces. A great lived example of this is A.H Rhume's process of publishing a book with another disabled friend for editing assistance. She shares her experience in this essay [104]. It is becoming (only slightly) more common to see HCI research engage with the possibility of mixed-ability teams and interactions (see [78, 105–107]).

1.7 Positionality & Reflections Throughout the Work

Reflexivity is a tool I highlight throughout this document. Chapter 2 Section 2.8.1 defines and discusses how researchers utilize reflexivity as a justice practice in their research. In each data chapter, there exists a positionality statement. Additionally, snippets of text from memos and journals throughout my PhD can be found herein (I am by no means done with my pursuit to understand justice, and this work represents only one point in time for my thinking). I hope this will give the reader context for my motivations, and surface my personal journey throughout the work.

1.7.1 Positionality

I am formally educated as an engineer and have been working in assistive technology research for eight years. I am multiply disabled but am primarily engaged in research with people who have disabilities I do not. I am a Ph.D. student in Computational Media, which is situated in an engineering environment. This interdisciplinary department bridges engineering perspectives with the Arts and Humanities. As such, I've had the opportunity to explore methods and histories from arts and humanities (See Chapter 4). Disability justice continues to be a place of learning and growth for me. So far, I know only what I know. I intend to continue learning from and participating in the community. My views will likely change or deepen. The line of inquiry detailed here has been a part of that process. My position has the potential to sway my research in favor of experiences similar to mine, but it also gives me the background needed to do this work. I have been an engineer, a researcher, an educator, a student, a care-giver, and a care-receiver.

1.7.2 Reflections on Motivations and Subject Choice

Note: italicized quotes in this section are from journals dated May 1 2022

I'm an assistive technology researcher. What that means has been many different things to me in my career.

> *What drew me to this field was care. I've done a lot of what I now know as care work in my life. I've functioned as an informal caregiver since I was a teen, sometimes solo, sometimes with the help of others. That's not something that I saw my peers struggling with, and all this time in and out of hospitals and working with low tech medical devices and processes gave me the thought that my skills as a technologist could help those who were chronically ill.*

Research in assistive technology was a way to apply my skills as a roboticist to big problems that felt good - that helped people. Based on the above reflection, I was well-meaning. When I first started in AT, it was because I was looking to apply technology advancements to a meaningful domain. We chose rehabilitation. We came in wanting to design a robotic wearable and found a population we thought would benefit, and built it without extensive engagement with the community. The work was interesting, but it would have been more fruitful to design with the community from the beginning. I now know that although it was done with the best intentions, my work in robotics was carried out with potential harm to the stroke survivors I worked with. This was just a part of my journey and I've continued to learn along the way.

As I've continued my work in this field I've noticed some trends. When I was first starting (and still), I asked myself questions and reflected on whether I should actually be doing this work and, if so, how to do it with grace and respect. Over the past two or three years I have had informal conversations with early career researchers who asked similar questions to the ones that I had been asking myself. We want to know how to do careful, good, slow research and many of us reflect on whether and how to. Further, I've shared many conversations with more middle-career researchers about how to onboard early-career researchers into this space. I've also had conversations with industry professionals who say that they want to do equitable work like this, but just don't know how to do it effectively in their company setting. These conversations have led me to take on actionable practices for my dissertation. An example reflection on the day of a conversation with an early career researcher can be found here:

> *So cool to see [redacted] in person too! I think a major thing from talking to them is knowing how to give back to the community and not be extractive, alternative dissemination, various ways and levels of impact, and wrestling with self? They asked me once how you justify that you are the one to do the work, and thats something I've asked myself a lot. I think thats a common trajectory for new researchers. I don't really know how to get that kind of data from anyone except through talking things out.*

There are researchers doing such good work in this field, but it seems many of us take long journeys to get there, doing imperfect and even harmful work along the way. In this dissertation, I explore these journeys, find valued practices, and find out how to onboard others.

1.8 Dissertation Outline

This dissertation is organized around three data chapters. So far, Chapter 1 has been an introduction and abbreviated background in which I have illustrated some core concepts essential to understanding the topic space. This background has been abbreviated because a more detailed background is included for each of the three data chapters. Further, Chapter 2 is both the first data chapter, and one that provides detailed coverage of the topic space.

Chapter 2, *Social Justice in HCI: A Systematic Literature Review*, explores how HCI publications have historically approached the topic of social justice and charts several useful considerations for future contributors to the space. These considerations can help future researchers frame and understand problems as well as decide how to approach them. They include (1) identifying harms and benefits. Many papers in our corpus were acting in response to harm. Fewer engaged with why those harms might be occurring, (2) identifying who harms and who benefits, (3) identifying sources of harm, (4) identifying levels at which to intervene (individual, communal, or systemic), (5) we end with highlighting a set of selected tools researchers leverage to enact justice: reminding researchers that even the mundane choices we make throughout our research processes can have implications for justice.

Chapter 3, *Disability Justice in Accessibility Research and Beyond*, explores the experiences and practices of people who bring a disability justice orientation into their lives and work. This series of interviews showcases specific research practices, individual's journeys with DJ, and their dreams for the future. Highlighted findings include (1) epistemic issues in technology development, (2) the importance of being in community with disabled people, and (3) why teaching DJ to technologists matters. These findings point us toward the values of the DREEM method, discussed next. The method helps technologists become enculturated with disabled communities, seeing disabled people as creators.

Chapter 4, *DREEM: Moving from Empathy to Enculturation in Disability-Related Human-Centered Design*, covers the iterative design of a method for empathy building with communities with disabilities. This method essentially helps designers to listen to disabled people and learn about disabled culture before engaging with them in a design context. The chapter highlights several iterations of the method, including applying it as onboarding for undergraduate researchers, and in large upper-division design courses. Generally, it seems to help researchers understand more nuanced experiences of disability.

Finally, Chapter 5 is the discussion and conclusion of this dissertation. In it, I summarize the findings of the three studies, and relate them to the research questions. In addition, I contextualize DREEM in relation to the findings of the interview study and the systematic literature review. I close with thoughts on my own journey and possible directions for future work.

Chapter 2

Social Justice in HCI: A Systematic Literature Review

- **Purpose within Dissertation:** This work is related to *RQ1: What are common practices for technologists who do justice and equity-based work?* In this project, we uncover what social justice-relevant HCI research is being done and how it is carried out.
- **My Role:** Co-lead on a team of eight - four faculty and four students. The group included: Ishita Chordia, Ashley Boone, Alyssa Sheehan, Lynn Dombrowski, Christopher Le Dantec, Kathryn Ringland, and Angela D. R. Smith
- **Other places this text might appear**: This text has been accepted to CHI '24 with the title *Social Justice in HCI: A Systematic Literature Review.* After the introductory section which positions the work within this dissertation, the article is included unaltered.

In this chapter, I discuss a systematic literature review of social justice in HCI.

Together with Ishita Chordia, I co-led an inter-institutional group of researchers. Over the span of a year and a half, we reviewed 243 full papers from top HCI venues. We systematically coded for the methods and approaches they used, their topics of interest, and more. Understanding this landscape of social justice in HCI is important to my broader dissertation topic in three ways.

First, it gives an overall picture of the field, allowing me to situate the smaller number of disability justice-related work within the broader context. Social justice has been a quickly growing term in HCI for the past 15 years, but DJ has been more recent. Only five articles related to disability at all, whether they called out DJ specifically or not. For comparison, out of the 124 papers that made it into our final dataset, 17 related to climate change.

Second, assembling the domains of justice allows us to share knowledge and practices across movements. We are on the same path, yet working separately. While we often have shared commitments and goals, theory is often not shared across movements. For example, planning and imagining better futures as an act of resistance exists in both disability justice and black feminist technoscience. Disability Justice writer and poet Leah Lakshmi Piepzna-Samarasinha uses the phrase ''dreaming" [85]. In other spaces, this concept is called ''futures literacy" [108], black futuring [109] or even ''speculative futurities" [110]. Pursuing justice in an academic space risks the tendency of academic siloing [111]. I'm hopeful that bringing social justice ideas together will resource us by helping us to learn from one another and develop together.

Last, disability justice is not a standalone movement. An explicit aim of disability justice is collectively moving justice issues forward. Four of the ten principles of disability justice, as defined by Patty Berne and the Sins Invalid collective, are about the importance of moving together with other movements. Those principles are Intersectionality, Anti-Capitalist Politic, Commitment to Cross-Movement Organizing, and Collective Liberation [4]. The full description of each can be found in more detail in Chapter 3

Disability uniquely intersects with all other aspects of life. As activist Mia Mingus describes, disabilities ‘’are all complicated by race, class, gender, immigration, sexuality, welfare status, incarceration, age and geographic location.” [11]. Likewise, justice is complicated by all of these things (i.e, the need for environmental justice is disproportionately apparent in low-income communities, leading to issues of illness and disability [112].) Disability justice began with the intention of centering voices of color, which had historically been few and far between in the disability rights movement. This combination of emphasis on intersectionality and collectively moving all justice issues forward makes disability justice unique. Mingus writes that she feels at home in the movement because she ‘’can engage in conversations about disability and race and gender and queerness and capitalism and more. [She] tried to look to the disability rights movement, but saw very few leaders who reflected [her], and found that, for the most part, disability was being talked about as an isolated single issue” [11]

2.1 A Personal History of the Project

Quotes within this first section are taken from a reflective journal dated May 8 2022

I left CHI '22 feeling confused. I attended workshops on disability justice, trauma-informed design, and many sessions that involved a social justice aspect (the keynote included). Tensions arose throughout those sessions in the conference and the conversations I had outside of them. Of course, everyone was coming from different perspectives, but they also seemed to be at different points in their understanding of justice.

These tensions were in clear display at a session meant to collectively define a social justice manifesto for the future of CHI [113]. It seemed we couldn't agree on what social justice should mean for our field. It became apparent that researchers in this area had not banded together, nor had they come up with solid definitions, tools, or techniques. I observed tensions based on career stage and between academia and industry; tensions between tenured, untenured faculty, and students; tensions between different ways of approaching justice (i.e Downward impact vs. upward impact); confusion over Justice vs Diversity equity and inclusion; and tensions about where our attention should be focused. Some spoke about justice for the communities we work with, some about justice for researchers or the systems we work within, and some about justice for others altogether.

At the time, I found the discord of ideas and values disorienting. I wanted to find out how we could come together to work towards justice in a more united manner. After going through with this study, I now believe this to be a positive. Our various thoughts and approaches may seem at odds to begin with, but we can work collectively toward these unique ideas of justice across domains. The experiences at this conference (and others since) have cemented the direction of my dissertation.

2.1.1 Focusing in on the Journey

I became frustrated and sad about our slow progress as a community. In a reflection from that day, I wrote: *''I just dont understand how people aren't TIRED. How is everyone so positive?"* I wrote about speaking with colleagues who all gave me valuable perspectives. I was repeatedly reminded that people were at different stages of learning. I was reminded that it's a slow and additive process. I was reminded that learning justice-oriented lenses takes work, and not everyone has done the work.

- After the keynote, I was upset that it felt like we were saying the same things repeatedly, and the people asking questions seemed so far behind and asking what seemed to me naive questions. *''Kate said, yeah, but think about the people in the audience who are hearing this for the first time. Its important that this is on the stage."*
- Later in the week, I was upset by attending a ... meet-up where many of the projects seemed to have technosolutionist and ableist undertones. The organizer (a friend) told me later *''that it is so important to have people in the same room. Lots of folks had probably not engaged with people doing critical work, and those of us in the room doing critical work dont engage with people doing mL diagnostics and tracking or whatever the hell unless its in writing."* I continued: *''So, damn. Good take. But sometimes I just dont have the empathy or emotional intelligence to be so bit-by-bit about it."*
- *''Lynns perspective is that yeah, we need to be pragmatic about the moves we are making towards social justice. And I think you can see that in her work,*

> *its a lot of practical steps. And Kate and Lynn are right - It is a process that is little by little. You cant do it all at once. ... people are in different places [But] Its a start that has measurable change and consequence."*

It was made clear to me that everyone was on varying stages of their own journeys to doing socially just research - these ideas shaped the goals of this dissertation. The following two sections highlight two aspects that lead me to engage in this work.

2.1.2 Connecting with Others

At the same conference, I made a friend who also felt confused and curious about the status of social justice in HCI. The best part of every conference I have been to is finding folks to make sense of it all with. We discussed the effects of everyone needing to be on the same page: how were we supposed to place our work within social justice? As two scholars who wanted to contribute to nonviolence and disability justice, where did our work stand within the web of social justice in HCI? How could we learn more about it if people needed to be more explicit about what they meant by social justice, or worse - if they were on different pages altogether? What tools and techniques should we use for our work going forward to ensure we follow socially just guidelines?

We decided to try to figure out what HCI researchers mean by social justice when they write about it. We gathered a team of esteemed researchers across seven institutions who all did different social justice related work. For 18 months, we performed a systematic literature review of papers that cover social justice in HCI. Collaborating with this team has been one of the highlights of my academic

Alt: A dense, colorful word cloud. The largest phrases are social justice, participatory design, social media, gender, feminism, activism, and civic engagement. Many smaller words give context for the literature review. These include solidarity, migration, food security, and many more.

Figure 2.1: Word cloud of author keywords from all the papers in our corpus

career. The results of our review follow.

2.2 Abstract

Given the renewed attention on politics, values, and ethics within our field and the wider cultural milieu, now is the time to take stock of social justice research in HCI. We surveyed 124 papers explicitly pursuing social justice between 2009 and 2022 to better reflect on the current state of justice-oriented work within our discipline. We identified (1) how researchers understood the social justice-relevant harms and benefits, (2) the approaches researchers used to address harm, and (3) the tools that researchers leveraged to pursue justice. Our analysis highlights gaps in social justice work, such as the need for our community to conceptualize benefits, and identifies concrete steps the HCI community can take to pursue just futures. By providing a comprehensive overview of and reflection on HCI's current social justice landscape, we seek to help our research community strategize, collaborate, and collectively act toward justice.

2.3 introduction

> *"If you have come here to help me, you are wasting your time, but if you have come because your liberation is bound up with mine, then let us work together."* Aboriginal activists group, Queensland, 1970s

The field of Human-Computer Interaction (HCI) is envisioning and building a more socially just future. There has been incredible growth in the area of social justice, as evidenced by the proliferation of justice-related terms and studies (e.g., racial justice, design justice, feminist studies, decolonial HCI, and more). At CHI 2022, where this project began, there were several workshops focused on collectively imagining what justice could look like in HCI research [113–115]. The keynote from Dr. Kishonna Gray urged us to *"pay attention to minority voices"* and look for *"precursors" to harm* [116].[*] There is a strong drive from within our community of technologists and researchers to move forward with equity and care.

Still, there is a disconnect between our future intentions and the field's current state. The disconnect is present because, as a field of practice and scholarly research, HCI does not have a shared understanding of how to work toward justice. This is evidenced by our ongoing discussions and reflections on our own and broader communities' ethical, scholarly, design, and research practices. For example, scholars have raised concerns about extractive practices when collaborating with community partners [117, 118], about who is cited [119], and about our review systems favoring authors with more privilege [111]. Junior researchers across many campuses have organized due to precarious living situations [120–123] and,

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[*] Looking for precursors to how our sociotechnical systems can be used to perpetuate societal harms and create new injustices allows for prevention instead of only reaction.

at the time of writing, many authors and reviewers are boycotting CHI 2024 [124].

We see these ongoing discussions as a sign of healthy and vibrant engagement with questions of justice. While our intentions toward justice are clear, we have some work to do in our scholarly and designerly practices and within our academic and professional systems. There is an opportunity to think more deeply about the horizon we are working towards and how we might take steps towards it [125].

The need for deepening our understanding of social justice is called out by Bellini et al.: "*there appears little critical discussion around what is meant by the justice inherent to social justice, despite there being calls to adopt such a lens*" [114]. These definitional tensions reflect the vibrancy of our ongoing conversations and indicate our discipline's commitment to the area and practice. We do not believe that HCI requires a single, coherent, unified definition of justice. Still, there is work to be done in our discipline as we strive towards justice. It is challenging to understand where our field should go without understanding where we are. What are our goals as a field when conducting such work? What commitments do we make? What practices do we espouse? What strategies can we use? How does a new researcher get started? Without a shared understanding, we limit our opportunities to reflect, collaborate across the field, strategize, and take collective action.

In this paper, we seek to understand how HCI research currently engages with concerns relevant to social justice so that we might better identify harm, acknowledge potential consequences, and work towards better futures. We review 124 full papers to understand (1) the landscape of harms and benefits that are currently being addressed, (2) the strategies researchers are taking to pursue justice, and (3) the tools researchers use to support thoughtful and equitable research processes. We contribute a set of key considerations that researchers can use to investigate justice-oriented questions and concerns and a discussion of directions the HCI community can take to address gaps and move towards more just futures. We hope this work sparks imaginations and seeds new ideas about how to support social justice work in HCI.

2.3.1 About our framing

To understand how contemporary HCI researchers conceptualize social justice, we planned to investigate how researchers explain and define *social justice*. We were surprised to find little explicit conversation of justice. Instead, we commonly found descriptions of the harms that require justice and social change, including *marginalization*, *exploitation*, *oppression*, and *vulnerability*. Uncovering how authors considered dimensions of social justice, including these harms and benefits (Section 2.6) and what level researchers acted on (Section 2.7), became the focus of our work in understanding how HCI researchers conceptualize social justice work. In doing so, we captured how authors in HCI pursued justice by reacting to problems of social injustice and the core tools they used to do so (Section 2.8).

We were conflicted in taking this approach. Centering injustice in this review could reduce people to the issues they face, leading future researchers into the trap of the deficit view [126, 127] or damage-centered design [128, 129]. We are further hesitant to use this framing as we do not want to implicate all authors within our corpus as reproducing harmful deficit or damage-centered narratives. At the same time, harm can serve as an entryway to begin considering social justice issues and measuring the impact of sociotechnical systems. Future research agendas can engage with injustice while focusing on joy, care, and wholeness [130]. With this work, we elevate the harms and injustices our community works to rectify, as well as the concerns plaguing certain historically marginalized groups.

2.4 Background

2.4.1 Turning Towards Justice in HCI

Alt: *Figure 2 is a bar graph that measures the number of papers in our corpus by conference from 2009 to 2022. The occurrences grow over time, and CHI is regularly the conference with the most submissions.*

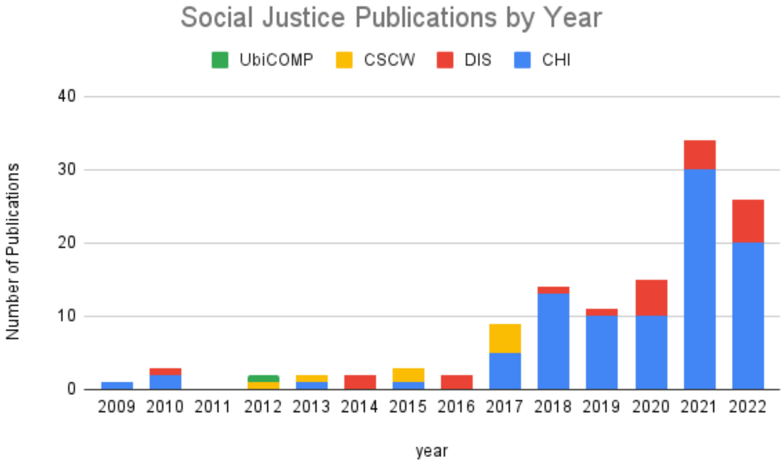

Figure 2.2: Increasing Number of Papers Using the Term "Social Justice" in HCI Publication Venues from 2009-2023. There were no papers before 2009 found.

In this section, we share a trajectory of social justice work in HCI to demonstrate how the field's core concepts relevant to justice have evolved. As early as the 1980s, HCI adopted Participatory Design from Scandinavian workplace environments to democratize design practice and strengthen end-users' influence on system development [131]. Participatory design emerged as a response to unilateral decision-making by management and made commitments to *"rebalance power and agency"* in the workplace [132]. Building on this work and recognizing a need to incorporate value commitments into the design process more intentionally, Friedman introduced Value Sensitive Design in 1996 [133]. While Friedman did not focus explicitly on questions of injustice, early work examined bias in workplace systems and found that biased computer systems can be *"difficult to identify let alone remedy because of the way that technology engages and extenuates them."* Friedman and colleagues concluded that *"biased computer systems are instruments of injustice"* and that *"freedom from bias"* should be amongst the select few values considered when evaluating computer systems [134].

As HCI moved beyond traditional workplace environments, HCI scholars showed increased interest in addressing complex social problems such as those concerned with economic and social development and environmental sustainability [125]. Early work in this area, however, promoted individual narratives of behavior change [135], technological progress at the cost of political and social sustainability [39, 136], and disempowering models of charity [125, 137, 138]. For example, some ICTD projects which aimed to support socioeconomic development internationally were critiqued for viewing "poverty" as a thing to fix [39, 125, 139] and *"perpetuating already-uneven economic relations by transforming individuals into consumers"* [39, 125, 136]. Critical scholars argued that without attending to system-level factors such as the distribution of power and privilege, design risked reproducing and perpetuating harm [30, 125]. Lin et al. asserted that HCIs tradition of building "*useful*" things was particularly insidious because it masked various forms of violence and social injustice behind narratives of progress [117].

Since the 2010s, HCI scholars have more explicitly taken up social justice as an orientation to doing HCI work (See Figure 2.2). Dombrowski, Harmon, and Fox describe social justice as an approach that attends to the *"ways that individuals experience oppression, including how benefits, burdens, obligations, power, opportunity, and privilege have been (in)equitably distributed within society"* [125]. When related to HCI, an approach to justice often means a concern for how systems of *"oppression, such as racism, sexism, ableism, ageism, classism, and so on, impact peoples experiences with technology, information, and design"* [140]. When doing this work, HCI scholars have turned to different strands of justice, such as Disability Justice or Transformative Justice [114]. These strands challenge complex systems of power and oppression and offer visions of more equitable futures. For example, Transformative Justice is a community-based form of justice developed by the LGBTQ+ community that centers on healing, accountability, and the transformation of harmful structures as a response to state-sponsored violence [141, 142]. Disability Justice interrogates how disability is conceptualized in order to advance inclusion and equity for disabled individuals [130, 143]. Bellini and colleagues refer to these various strands of justice as *"mosaics"* because while distinct, they are *"tightly interconnected"* and *"demonstrate the complex patterned nature of social justice HCI"* [114]. A focus on social justice in HCI often refers to a focus on the complex pattern of marginalized experiences, identifying systematic oppression and pressures, and identifying new, prefigurative futures. HCI scholars have proposed various frameworks to explore the role design can play in helping us move towards these mosaics or visions of justice. Irani and colleagues, for example, introduced postcolonial computing as an orientation to design work that centers the role that *"global power, wealth, economic strength, and political influence"* play in shaping cultural encounters in *"the developing world"* [39]. We discuss more about these frameworks as a tool for pursuing social justice in Section 2.8.

While the HCI community is having encouraging conversations about justice, they remain surprisingly disparate [114]. Independent progress is being made within separate strands of justice, making it challenging to build shared understandings and learn from one another. It is a great time to reflect on the current landscape and consider how we might want to move forward as a scholarly community. This paper reviews how relevant scholarship describes and engages with justice-oriented concerns. We identify the harms and benefits currently being addressed, the strategies researchers employ to address injustice, and the tools they use to support justice-oriented work. Collectively, these offer us a set of key considerations with which to think about social justice in HCI.

2.4.2 Conceptualizing Systems of Power

Social justice work requires attention to the broader social and political systems that produce injustice because technology often embeds and reproduces these systems. Black feminist scholar Patricia Hill Collins introduced the Matrix of Domination to examine how society structures power. Collins conceptualized race, class, and gender as interlocking systems that shape the lived experiences

Alt: *Figure 3 is a visualization of the intersecting axes of oppression. The axes appear as spokes on a wheel. At one end of each spoke is a position of privilege, and the corresponding position of oppression appears at the other end. In the center of each spoke is the action. For example, pale vs dark, colorism.*

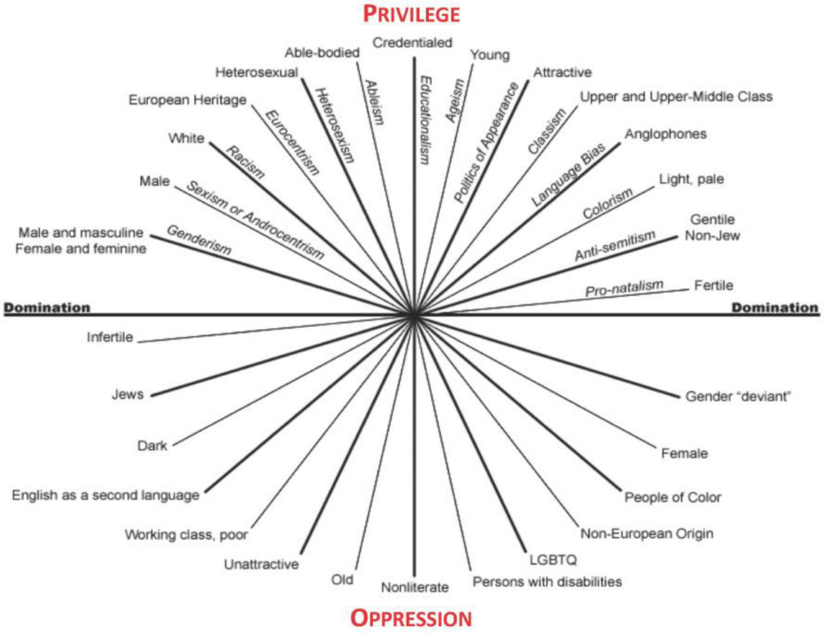

Figure 2.3: The intersecting Axes of Oppression as adapted by [1] from Morgan's Axes of Oppression [2]

of Black women and other intersectional identities [144]. Collins also explains that individuals experience and resist oppression on three levels: the personal, the communal, and the institutional [144], which we will further unpack in the findings section.

Black feminist legal scholar Kimberlé Crenshaw introduced Intersectionality as a theory in 1989 [145]. Yet, as Rankin and Thomas acknowledge [146], Intersectionality's history originates before Crenshaw. The Combahee River Collective Statement is often acknowledged as one of the first recorded discussions of Intersectionality [147]. Crenshaw discusses how those with multiple marginalized identities experience oppression as an additive, compounding phenomenon rather than a singular, disconnected phenomenon. Indeed, "*the intersectional experience is greater than the sum of racism and sexism, so any analysis that does not take intersectionality into account cannot sufficiently address the particular manner in which Black women are subordinated*" [145].' The idea has picked up momentum within academic and activist circles. For example, Disability Justice activists list intersectionality as their first and primary principle, along with a refrain from poet activist Audre Lorde: "*We do not live single issue lives*" [130].

Morgan, a gender studies scholar, developed the Axes of Oppression in 1996. The axes visually represent how systems of oppression privilege some identities and oppress others [2] (the top half of Figure 2.4.2 radially displays identities that hold power and privilege while the bottom half displays identities that have the potential to be oppressed due to the systems of oppression, such as racism and ableism). Privilege and oppression are unevenly distributed amongst individuals and communities based on their position within the axes of oppression. Morgan writes that this position is "*simultaneously a locus of our agency, power, disempowerment, oppression, and resistance*" and shares the necessity for "*both awareness and honesty with respect to our own positioning on the various axes of this grid*" [2].

Systems of power are intertwining and additive in ways that make it challenging to see, engage with, account for, or attempt to remedy the unequal distribution of benefits and harms that they produce [30]. By focusing on lived experiences of benefits and harm, we deepen our understanding of how systems of power manifest for individuals and populations. Furthermore, scholars have noted that a focus on the lived experience "*is a useful way to establish what is meant by harm, and indeed in gauging or deciding ways to measure it*" [3]. In this paper, we examine the distribution of benefits and harms as a way to conceptualize and do the work of justice.

2.5 Methods and Context

2.5.1 Data Collection and Analysis

To develop our corpus, we collected articles that explicitly discussed "justice." We built on Bellini et al.s observation that the many mosaics, or strands, of justice"*demonstrate the complex patterned nature of social justice HCI*" [114]. Bellini et al. list five such mosiacs: citational justice [119], research justice [148, 149], disability justice [130], restorative justice [150], and environmental justice [151, 152]. Building on this insight, we created a search query by concatenating these five mosaics with four others that we are familiar with as HCI researchers: transformative justice [141, 142], reproductive justice [153], economic justice [154], and racial justice [155, 156]. We searched the ACM Full Text Collection using this initial query, selected a random 20% of the resulting set, and iteratively added search terms as they appeared in this subset. We identified six additional mosaics (structural justice [157], distributive justice [158], information justice [159], intergenerational justice [160], language justice [161], design justice [30]) and searched the ACM Full Text Collection using this final query in February 2023:

> "social justice" OR racial justice OR disability justice OR restorative

> justice OR citational justice OR research justice OR environmental justice OR transformative justice OR economic justice OR reproductive justice OR structural justice OR distributive justice OR information justice OR intergenerational justice OR "language justice" OR "design justice"

We acknowledge that this list is not exhaustive. During the coding process, we came across additional mosaics that were not included in our final query, including mob justice [162], testimonial justice [163], and hermeneutical justice [163]. Furthermore, we found that terms such as “marginalization” and “oppression” were commonly used in justice-focused research but were not included in our query. Our approach only captures research that clearly labels itself as social justice-oriented, and while this is a limitation of this survey, we were able to identify a meaningful number of papers that nevertheless provide valuable insights.

To bound the corpus to a manageable size that still covered topics across HCI, the research team chose to restrict our search to four keystone conferences: CHI, DIS, UBICOMP, and CSCW. While we acknowledge that justice-related conversations are happening in many different venues, we believe the four chosen venues cover the breadth of research in HCI and capture our core conversations [*]. We further excluded papers if the primary goal of the work was not justice-oriented. Papers were excluded from the corpus based on four criteria:

1. Justice was discussed strictly by participants (e.g., as a participant quote).

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[*] To capture a broad overview of HCI, we did not include domain-specific venues (i.e., FAccT, ASSETS, VIS, etc.).

2. The justice-related term was used strictly as an example (e.g., *"...representation, beauty, language, self-transcendence, subjectivity, creativity, interpretation, identity, self-determination, and social justice, among others"* [164])
3. The justice-related term was only used in the discussion or conclusion as a direction for future work rather than as a goal of the current paper.
4. The justice-related term was used without a discussion of the *"ways in which people experience oppression and marginalization"* [140]. For example, ICTD papers that lacked a discussion of colonialism or marginalization were excluded.

103 papers were removed due to one or more criteria, and 36 borderline papers were flagged for review. Borderline papers were discussed during weekly team meetings, and decisions about whether to include or exclude were made by consensus. Our final corpus included 124 total papers, 93 from CHI, 22 from DIS, 8 from CSCW, and 1 from Ubicomp, which spanned the years 2009 to 2022. We have attached a complete citation list of all publications in our corpus in Appendix .2. An overview of the corpus can be found in Appendix .1: corpus at a glance.

Four members of our team went through three rounds of coding to ensure consistency across the corpus. In the first round, we coded 10% of the corpus. For each paper, four authors independently coded the paper and met weekly to discuss challenges and necessary changes to the codebook. In the second round of coding, we tested the codebook on another 10% of the corpus where each paper was independently coded by two of the first four authors. Our iterative process helped us refine our questions and address the most salient factors. In our final round of coding, all 124 papers in the corpus were independently coded by at least one of the four first authors. The final set of codes collected for each paper included: (1) the title, author, year, publication venue, and contribution type; (2) the problem statement; (3) where or if the paper explicitly called out justice; (4) frameworks employed; (5) methods; (6) participants; (7) the type of oppression addressed by the paper (guided by the Axis of Oppression); (8) the approach used by the researchers to resist oppression; (9) the material benefits to the participants; and (10) self-disclosure, reflexivity, or positionality statement.

Guided by Braun and Clarkes approach [165], we then conducted a reflexive thematic analysis. Reflexive thematic analysis is an approach to analyzing data that acknowledges and "*fully embraces the subjective skills the researcher brings to the process*" [165]. Through the screening, data extraction, and analysis processes, the first four authors kept independent memos to note questions, reflections, and insights. The notes in these memos, particularly those involving edge case papers, seeded rich conversations during weekly team meetings over five months and helped evolve our understanding of the corpus. We analyzed our final set of codes inductively, where each researcher took two or three of the ten codes listed above and analyzed them using affinity diagramming. We used weekly team meetings to gather feedback on our analysis, share insights, discuss alternative interpretations, and ultimately settle on the core themes reported below.

2.5.2 Positionality

Our driving motivations behind this paper stemmed from our collective interest in understanding how best to pursue socially just aims in our own work and positioning that work within the broader context of social justice in HCI. As community members, we have been inspired by the changes occurring in our field. We wanted to write a love letter to the community highlighting our progress and making room for more. As individuals who care deeply about the uptake of justice, we hoped to orient ourselves and others to the many discussions in our field.

Our team consists of eight researchers, four graduate students, and four faculty members across six academic institutions in the United States. Members of our team have struggled with the effects of marginalization in a multitude of contexts as researchers and beyond. We are each pursuing social justice research in different contexts, including civic technology, community activism, workplace technologies, mental health as well as race and disability. Some of us were more comfortable with taking on the identity of being a social justice researcher, while others were coming to terms with framing their work in that manner.

We are each a part of the HCI community which we have surveyed. Several authors wrote papers that were included in our corpus. Additionally, we knew many of the authors in our corpus as colleagues, which may have influenced how we perceived their work.

Recent calls from within the community have been made to avoid CHI 2024 in Hawaii based on a history of colonialism, over-tourism, environmental degradation, and the recent devastation in Maui [124]. Our decision to submit to CHI this year was not taken lightly. While our team members have chosen to withhold several other publications, we struggled with the irony of withholding a social justice paper in this context. The call to support Hawaiians desires highlights our communitys need to contend with justice. It is a reminder that we are part of a system that can be harmful to communities and perpetuate power imbalances. We also weighed the professional impact on our careers and academic pursuits as a blended group of junior and senior researchers, some of whom felt pressured to publish as early-stage professionals. The professional, political, and ethical tensions around publishing illustrates the potential precarity of enacting justice-oriented work for those with less privilege.

Throughout this project, we grappled to understand the current state of social justice research and its practices. In the following sections, we share how our field conceptualized social justice through harms and benefits, explain how researchers approached change on multiple levels, and show some concrete tools they used.

2.6 Harms and Benefits

> "*Most design processes today therefore are structured in ways that make it impossible to see, engage with, account for, or attempt to remedy the unequal distribution of benefits and burdens that they reproduce.*" - Sasha Costanza-Chock, activist, researcher and designer [30]

In this section, we map conditions of injustice that authors responded to by sharing how authors discussed: (1) the form of harms and benefits, (2) who is being harmed and who benefits, and (3) where researchers locate the cause of harms and benefits.

While conducting this analysis, we found that authors disproportionately framed their work around harms rather than benefits. While 102 out of 124 papers included a discussion of harm in their paper's introduction, only 34 included a discussion of benefits, which remained limited even when included. Even though there was limited data on benefits in our corpus, each aspect of harms and benefits introduced in this section includes a discussion of how benefits were brought to light.

2.6.1 Harms & Benefits Addressed

Forms of Harm

In order to identify what forms of harm are being addressed by HCI researchers, we turned to zemiology, the study of social harms [3, 166]. Zemiology emerged from critical criminology as a way to highlight the range of harms experienced by society that extends beyond those that are caused by crime. Canning and Tombs provide a provisional typology of social harms, which we use to understand the lived experiences of injustice that are addressed by the papers in our corpus [3]. The typology included physical harms, psychological and emotional harms, financial and economic harms, cultural harms, harms of recognition, and harms of autonomy. In addition to their typology, we have included environmental harms, which was a category addressed by several papers in our dataset and reflects HCI's nascent turn to non-human impacts of computing [167–169]. A full description of each category, along with examples of how these harms appeared in our corpus, can be found in Table 2.1. In line with Canning and Tombs, we emphasize that these categories of harm are not mutually exclusive, but rather, are complex, interrelated, and synergistic.

Table 2.1: Examples of each form of harm found in our corpus. Definitions are based on Canning and Tombs typology of harm [3]

Category	**Definition**	**N**	**Examples**
Physical harms	Injury, illness, or death	24	police brutality [170], domestic violence [114, 171], "suboptimal vaccination" [172], "lives lost due to violence" [173], "increase in diet -related diseases, as well as rising hunger and malnutrition rates" [174], "physical or bodily injury or harm, including gun violence that results from conflicts between individuals or groups" [175]
Psychological & Emotional Harms	Psychological states or emotional impacts of traumatic events or ongoing distress.	29	"added emotional and cognitive burden of teaching otherwise well-meaning supporters about the nature of their experiences" [176], "damaged social and self-esteem" [177], "impair the psychological well-being of human moderators " [178], harassment [162, 177, 179–181]

Financial & Economic Harms	Monetary harms that affect individuals, households, or wider communities.	20	"barrier to getting a job" [182], "hidden fees and social media gamification strategies that compel unwanted financial risk" [183], wage theft [184], "overproduction and free trade agreements flood and destroy local markets of developing and developed countries alike" [174], "low wages, and lack of hazard pay," [178]
Cultural Harms	Destroy, undermine, or impose a particular culture	3	"Influence of the dominant cultures in shaping the global trends of visual design" [185], Ubicomp's colonial impulse [186]

Recognition Harms	Reduced, distorted, or negatively impact people's ability to engage in society.	45	criminalization and stigmatization [187], "stigmatized topic of menstrual health" [188], "sidelined or erased the roles, experiences, and contributions of people of color" [189], "Asian Americans and Pacific Islanders (AAPIs) are perceived as the model minority with a monolithic identity," [190], "Colonial tropes characterizing certain people as in need of enlightenment, civilization, and development" [39], "othering or erasing non-binary respondents" [191], "marginalize the viewpoints of people with complex communication needs." [192]

Autonomy Harms	Reduced capacity, opportunities, or potential for self actualization	43	“inequitable access to basic human rights (e.g., health care, education, housing, employment opportunities)” [193], “excluded from accessing care” [194], “impede disabled peoples already limited access to public space” [195], “work is often invisible or not valued” [196], “lacking in some aspect of digital access” [197], “limiting Native American individuals potential for political engagement through digital means.” [198], “taboos generated by the marginalization of women directly inhibit speech and information seeking” [199],
Environmental Harms	Arise from human interaction with other species and the natural environment.	8	“local air pollution” [200], “Sea-level rise” [201], “urban heat” [202], “unsustainable food system, air pollution, contribution to climate change, loss of biodiversity, and low animal welfare.” [174]

In our corpus, researchers paid the most attention to recognition harms, referring to ones ability to engage in society (n=45), and autonomy harms, referring to blocked capacities and self-actualization (n=43). The attention to these two forms of harm reflects a broad interest in the field of power, identity, and access. While recognition and autonomy harms are important and require extensive attention, other forms of harm have been understudied. Less attention was given to environmental harms (n=8) and cultural harms (n=3). The lack of discussion around these forms of harm indicates a dearth of language for talking about lived experiences under environmental and cultural turmoil. Colonialism, despite being widely addressed within our corpus, was often related to recognition harms, contending with identity aspects of colonialism. "*Harm that arises through the destruction or undermining of particular cultures or ways of being*" [203], and "*harms that result by the imposition of a particular culture*" [3] were rarely attended to in the framing of social justice work. In addition, we observed little attention to environmental harms, particularly harms that impact non-human individuals, including animal and plant life and broader ecologies. Without explicitly naming these harms, we constrain our discussion of environmental justice to a human-centered one.

Many papers also carefully attended to the complexity of harm. Of the 102 papers that included a discussion of harm in the introduction, 52 discussed multiple interrelated forms of harm. For example, Lu et al. contributed a rich description of the ways surveillance manifested in forms of psychological and emotional harms (student feelings of discouragement and embarrassment), harms of recognition (reducing students actions to misbehavior), and autonomy harms (penalizing students, especially students with disabilities) in the classroom context [204]. Additionally, we found cases where one form of harm contributed to harm of a different form. Harms associated with racial profiling highlighted the possibility for recognition harms to produce physical harms in the form of injury or even death. Bosley et al. argued that technological solutions and design interventions in policing "*are often rooted in the continued racial profiling of poor and socially marginalized communities*" [170]. In this case, racial profiling, a harm of recognition, combined with structural police violence, met to create physical harms that disproportionately impacted poor and socially marginalized communities. We encourage authors in HCI to continue to attend to rich, complex accounts of the many forms that harms take.

Careful attention to forms of harm is important because forms of harm frame problems of social injustice. Shifting the problem frames we use to conceptualize social injustice shifts how we pursue social justice. Pei and Crooks, for example, argued that approaching the digital divide as a problem of distributing digital access constrains the solution space and ignores the social inequalities that root technical disparities, ultimately failing to produce equity [197]. Framing the digital divide as an economic harm or a harm of recognition as opposed to a harm of autonomy produced a different understanding of the experience of digital connectivity and implied an alternative solution space. Thinking about how we frame problems, including their interrelated and additive dimensions, can illuminate new perspectives for thinking about social injustice and the approaches we use to address it.

Forms of Benefit

Mirroring the discussion of harms, papers in our corpus also discussed benefits. The ability for technology to broadcast information and capture attention was discussed as a benefit of recognition, an ability that afforded power and increased the ability for individuals and groups to engage in society [205, 206]. In addition, it was widely recognized that technology has the potential to increase access to information [207] and resources [208, 209] – benefits of autonomy. Other forms of benefits, such as positive health outcomes [210], financial benefits such as employment [211], and psychological and emotional benefits like feelings of safety [171] were also referenced in our corpus.

Discussions of benefits, however, remained limited. A common pattern was to acknowledge that technology produced benefits and then identify the limitations of that technology that also produced harm. For example, Tuli et al. discussed how menstruation trackers benefit people who menstruate by facilitating a better understanding of ones body, avoiding stigma around staining, and providing a resource for natural birth control [212]. However, the same systems contributed to the medicalization and control of menstruating bodies. These examples illustrate a pattern in the discussion of benefits in our corpus: they emphasize the positive potential of technology while critiquing elements of its current form.

2.6.2 Who is Harmed and Who Benefits

Table 2.2: Examples of populations or groups of people that were identified as experiencing harm in our corpus

Analysis	**Definition**	**N**	**Examples**
Intersectional Analysis	Examine harms to a group of people with attention to the way that multiple identity characteristics intersect	17	"Black women and femmes" [213], "Low resourced job seekers, specifically those with neither social networks nor digital literacy" [182], "Persons with disabilities from the Global South" [214], "Women in the Global South" [162, 215]

Single axes	Examines harms to a group of people based on a single identity characteristic	50	Women [171, 205], Women experiencing menopause [199], "Non-cisgender" [216], "Transgender and non-binary people" [217], "Transmen" [218], "BIPOC (Black, Indigenous, People of Color)" [176, 219], "Black and Brown communities" [170, 189], "Black and Latino/a/x communities" [175], "Asian Americans and Pacific Islanders (AAPIs)" [190], "Native American Individuals" [198], "People with disabilities" [195], "People with disabilities and specifically vision impairments" [207], "People with ADHD" [126], "Individuals with health conditions (e.g., stroke, cancer, abuse, depression) that affect their ability or willingness to engage alongside researchers and verbally express themselves." [192], "Older adults" [220–222], "Youth" [223], "Students" [204, 224], "Sex workers" [173, 187, 225], "Home health aides" [226, 227], "Crafters" [211], "Content moderators" [178], "Migrants" [228], "Refugees and migrants" [229]

Who is Harmed

Harms are not experienced evenly across populations; they disproportionately affect those on the periphery of power. 67 of 124 papers named a clear group that experienced disproportionate harm (see Table 2.2).

The majority of papers in our corpus discussed single-axis identities. Researchers most commonly focused on working identities as well as social identities. Social identities such as gender [171, 196, 199, 205, 212], race [170, 175, 176, 189, 190, 198, 219], and ability [126, 192, 195, 207] received significant attention, while there was less attention on the challenges that trans and nonbinary people [216–218], LGBTQ communities [230], and older adults [220, 221] face. Papers which focused on people's working identities primarily discussed invisible work, such as that done by artists and crafters [211], mothers [231], and health workers [226, 227], and hazardous work, such as that done by content moderators [178] and sex workers [173, 187, 225]. Many marginalized identities have received little attention from social justice researchers in HCI. Some examples include indigenous people, unhoused people, non-citizens, people with large body sizes, and religious minorities.

Only 17 of 124 papers in our corpus discussed harms related to intersectional identities [145]. In this category, we included papers that addressed how the distribution of harms manifests across multiple factors of identity. Attention to intersectional identities in social justice work is important because it often reveals uniquely felt forms of harm. For example, Kirabo et al. explore the unmet transit needs of disabled people in Kampala, Uganda, which do not match the unmet needs of disabled people in countries that are better represented in HCI literature. This mismatch frequently leads accessibility interventions designed in the Global North to fail when implemented in the Global South [214]. As another example, Musgrave and colleagues explore the unique form of harassment experienced by Black women online [213].

This imbalance replicates the findings of a systematic review of identity in CHI between 1982-2016, which found that research during this time tended to address a single facet of identity at a time rather than intersectional identities [232][*]. All 17 papers in our corpus that addressed intersectionality were published after 2018, and 11 of these were published between 2021 and 2022, indicating a growing response to the lack of intersectional analysis observed in 2017. Overall, intersectional identities remain understudied in the context of social justice work.

Who Benefits

Opposite to those who are harmed on the Axes of Oppression (see Figure 2.4.2) are those who are privileged. In our corpus, it was rare for papers to engage with those who benefit from social structures. One exception was authors who sought to change the behavior of the privileged and the powerful. For example, Luckoff et al. aimed to promote paternal engagement in family life via technological cueing, addressing labor imbalance by gender in families by increasing the amount of labor performed by men [231]. Any paper in our corpus that focused on the behavior change of researchers (via developing better methods, etc.) similarly en-

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[*] Work in HCI relating to intersectionality has been critiqued for failing to cite and recognize Black women researchers as well as its true origins (also discussed in Section 2.4.2) [146]

gaged those who are in positions of power [191,233]. Another exception occurred when authors in our corpus spoke of the uneven distribution of harm and benefit between groups. Matias et al. highlighted how male voices receive more attention than females in social media, resulting in silencing women's voices [205]. Corbett and Loukissas set up a clear dichotomy between the gentrifiers and the gentrified: the distinction between which is rooted in systems of power that distribute privilege and power among dimensions of class and race [234]. While these examples showcase researchers moving towards engaging groups that receive social and material benefits, many questions remain. How do benefits contribute to the perpetuation of social injustice? Can those benefits be distributed more evenly? How can groups that benefit be engaged in working towards social change? More work is needed to understand the role technology can play in engaging the powerful and the privileged in concerns of justice.

2.6.3 Sources of Harms and Benefits

Sources of Harm

70 out of 124 papers included an explicit explanation for why harm is occurring. Authors located the harm within sociotechnical systems (n=19), processes of design, research, and making (n=19), and social and political structures of oppression (n=35). Full descriptions of each category, along with examples of how they appear in our corpus, can be found in Table 2.3.

Table 2.3: Examples of how authors in our corpus explained why the harm was occurring

Source	**Definition**	**N**	**Examples**
Sociotechnical Systems	Authors explain how the particular features or affordances of a sociotechnical system contribute to harm	19	"As crucial responsibilities are increasingly transferred to computer systems, however, systems of public consequence are "black boxed by closed-source code, security-by-obscurity policies, outsourcing to private companies, or simply closed door agency processes that exclude public participation and oversight." [235], "AI-powered analysis of faces, bodies, and associated data" [236], "Apps are being imbued with their designers interests, opinions, biases and assumptions about self-care." [237], "The biometric point of sale (POS) machine in the administration of food security in Indians public distribution system" [238], "ClassDogo...popular digital intervention for classroom management" [204]

Processes of Design, Research, and Making	Authors explain how methods or approaches to design, research, or making contribute to harm	19	“HCI is increasingly working with vulnerable people, yet there is a danger that the label of vulnerability can alienate and stigmatize the people such work aims to support.” [230], “Research aims which privilege neuro-normative outcomes.” [126], “The incorrect assumption that knowledge produced is applicable to all genders when the data only justifies generalization to one gender group.” [239], “Community based participatory research [240], “researchers working with marginalized communities” [148], “community based research” [233], “Rushing to build and deploy AI systems, without first examining the knowledge, needs, and perceptions of the paraprofessional workers that will be expected to operate these systems within marginalized communities” [241], “Neoliberal design logic” [242]

Social and Political Systems of Oppression	Authors locate the cause of harm in broader systems of power	35	“Structural racism, classism, patriarchy, and other systems of oppression have rendered breastfeeding a luxury good, more easily accessible to privileged families.” [210], “Domestic work is visible or invisible in a society due to many cultural, social and conventional factors.” [196], “Legacies of structural racial inequity.” [183], “Rooted in violent inceptions from the human trafficking and exploitation of Africans and subsequent economic and social inequality and discrimination. These historical trajectories are important for contextualizing online harassment not as a contemporary issue caused by technology, but as existing structural inequalities that are boosted and bolstered by technology.” [213]

The most common explanation of harm was broader social and political systems of oppression (n=35). Felice et al. identified menopause as a matter of social justice due to the *“intersecting gender- and age-based marginalization that people* *going through menopause still experience"* [243], and Musgrave et al. explain that "*Online harassment relies on underlying hierarchies of power, privilege, and discrimination based on characteristics like sex, race, and gender*" [213]. These explanations situate the causes of harm not in technology but rather in social and political systems and, ultimately, a histories of oppression.

19 papers identified sociotechnical systems as a source of harm. For example, Lu et al. detailed how the key affordances of ClassDojo, a behavioral management technology, contributed to harm around surveillance and threats to student privacy [204] and Whitney et al. discussed how the public is excluded from decision-making by closed-code algorithms which limit *"public participation and oversight"* [235]. In this case, the lack of transparency in algorithms and their interfaces contributed to exclusion, a harm of (the lack of) recognition. In each of these examples, researchers paid close attention to how specific design choices contributed to harm. Furthermore, there is awareness and acknowledgment that sociotechnical systems encode broader systems of oppression- many papers point to the ways that technology "*embeds, enables and enacts"* systems of oppression [176, 194].

19 papers in our corpus identified processes of design, research, and making as a source of harm. In presenting a framework for social justice-oriented interaction design, Dombrowski et al. argued that "*explicit engagement with social justice can help guard against*" the tendency to "*design for the status quo*," which "*often leads to the re-entrenchment of problematic inequalities and power relations*" [125] and Spiel et al. argued that "*Technology research for neurodivergent conditions is largely shaped by research aims which privilege neuro-normative outcomes*" and

characterize ADHD experiences as disruptive [126]. This set of papers focuses on the role of researchers and designers in causing harm.

The corpus demonstrates a clear awareness of the links between different explanations of harm. In the 70 papers that gave explanations of harm, we saw thoughtful links between sociotechnical systems, the processes of design, research, and making that shape them, and the broader social and political systems they operate within. Musgrave et al., quoted above arguing that online harassment is rooted in a long history of discrimination in the US, go on to explain that "*These historical trajectories are important for contextualizing online harassment not as a contemporary issue caused by technology, but as existing structural inequalities that are boosted and bolstered by technology.*" We hope to see HCI researchers continue to engage with this complexity, even as they focus their work on addressing harms located at these different sites. When we discuss harm without identifying the source, we absolve ourselves of responsibility for contributing to harm and obscure the possibility of alternative futures. We encourage authors to be diligent about explaining how harm occurs and to be thoughtful in choosing where they want to have an impact.

Sources of Benefit

15 of the 34 papers that included benefits discussed benefits as produced by technology. For example, virtual reality has created new opportunities to *"present, express, and experiment ones identity"* [216], assistive technology has increased *"access to information and participation on social media,"* [207] and sales platforms like Etsy have provided opportunities for employment [211]. Despite aware-

ness of the potential for technology to cause harm, there remains optimism within the field about the positive potential of technology.

The 19 other papers that included benefits either did not explain the sources of those benefits (10 papers) or the source of the benefit did not clearly fit into the framework we used to organize sources of harm (9 papers). There was a range of benefits that came from various social practices, including street outreach work [175], conversation facilitation tools [244], paternal involvement in heterosexual parenting [231], civic engagement [245], and education [246]. More work is needed to unpack sources of benefit and examine the ways in which they may be fundamentally different from sources of harm. It is especially important to understand systems, structures, and processes that allow some to benefit from harm to others, as these systems are key in the continuation of harm.

2.7 Approaches to Pursuing Justice

> *"...people experience and resist oppression on three levels: the level of personal biography; the group or community level of the cultural context created by race, class, and gender; and the systemic level of social institutions. Black feminist thought emphasizes all three levels as sites of domination and as potential sites of resistance."* [144] - Patricia Hill Collins, Black Feminist Sociologist

We turn to Patricia Hill Collins to understand the levels at which HCI is resisting oppression [144]. Collins emphasizes that oppression is not limited to one level but operates at multiple levels simultaneously, and by recognizing how oppression manifests at the individual, community, and systemic levels, we can develop more effective strategies for resistance. Our corpus shows researchers pursuing justice at all three levels, sometimes independently and interdependently. Here, we discuss the strategies researchers use to pursue justice at the individual, community, and systemic levels.

2.7.1 Individual

At the individual level, people experience harm due to relationships, individual experiences, and personal beliefs [144]. Researchers in our corpus explored how sociotechnical systems can shift individual experiences of harm by influencing interpersonal relationships or individual belief systems. For example, some researchers investigated the role technology can play in shifting personal dynamics in interpersonal relationships. Dhaundiyal examined the distribution of domestic labor in India during the COVID-19 lockdown and prototyped a tool that makes the invisible work done by women more visible to the rest of their families [196], thereby mitigating the harm of recognition. This tool was designed to *"initiate discussion among the family members that could break the cycle of continued gender inequalities."* Sultana et al. also designed a tool to support women who are victims of online harassment. This tool captures evidence of the harassment and empowers them by providing authenticity and credibility to their claims [162]. While underexplored in our corpus, these examples demonstrate the role that technology can play in building awareness about the inequitable distribution of power between individuals. We also saw a very small number of studies (n=3) where researchers used technology to support victims in coping and sense-making in the aftermath of a harmful experience, reducing psychological and emotional harm. To and colleagues used novel prototypes to explore the role ICTs can play in helping BIPOC individuals cope and respond to racist micro-aggressions [219]. Similarly, Dimond and colleagues explored how online storytelling can help individuals make sense of a traumatic experience [180]. Studies at the individual level represent what Collins refers to as changes to the *"individual consciousness,"* an important site of resistance [144]. Approaches targeting the individual level were the least represented, making up less than 10% of our corpus. There is an opportunity for HCI to explore further the ways technology can shift experiences of harm at the individual level by building awareness, supporting reflection, and educating processes that change how we think about ourselves and each other.

2.7.2 Community

Each individual is a member of certain groups based on their factors of identity. Those groups have their own cultures, norms, histories, knowledge, and social institutions. People experience harm at the community level when the group's knowledge, norms, and ways of being are oppressed or controlled [144]. Researchers working at this level surfaced how sociotechnical systems can contribute to such oppression or serve as a tool for resistance [30]. Approaches targeting the community level were the most represented in our corpus, appearing in over half of the studies. Researchers often sought to understand how a specific technology does not work for a certain community. For example, Bennett and colleagues explored how smart scooters and autonomous delivery robots create obstacles for those with disabilities [195], an autonomy harm, and Cunningham et al. investigated the ways that mobile banking applications inequitably serve Black communities [183], a financial and economic harm. We also found examples where researchers asked a specific community about their experience of harm, healing, and joy online and the design interventions they would like to see [177, 213]. Additionally, researchers highlighted examples of communities self-organizing and using technology to pursue justice. In contrast to research exploring technology's role in supporting or oppressing groups of people, this work sought to understand how communities are already adopting and appropriating social technologies to further their own visions of justice. This included understanding how older bloggers are combating ageism online [220] and the way that Venezuelans are using Facebook to barter for basic needs in a troubled economy [247]. While these studies were less common in our corpus, they demonstrate a bottom-up approach to doing community-level justice work. Instead of asking what HCI researchers can do for the communities we work with, bottom-up approaches sought to identify and amplify the work that is already being done by these communities.

2.7.3 Systemic

When Patricia Hill Collins discusses oppression at the systemic level, she specifically discusses formal organizations such as educational institutions, which *"represent the dominant groups standpoint and interest"* and subjugate others to those interests [144]. Fortunately, we saw many examples of researchers problematizing existing knowledge, frameworks, and methods used within HCI. For example, Dourish and Mainwaring critiqued ubiquitous computing, highlighting how colonialism is entwined with *"how we think, how we talk, and how we work"* [186]. Pei and colleagues illustrated how the *"digital divide framework"* perpetuates inequity by ignoring startup, maintenance, and affective costs accompanying digital access. Researchers also discuss structural challenges in the practice of research and how, for example, community-based research can be extractive and constrained by the funding and timelines of academia [148, 240]. Researchers working at the systemic level introduced new methods and frameworks that centered the viewpoints of historically marginalized groups. For example, Lazar and colleagues introduced *"making"* as a method that can center the viewpoints of people with complex communication needs [192] and Chen and colleagues introduced *"trauma-informed computing"* to better account for the role that trauma plays in peoples interactions with technology [248]. At the systemic level, a rich amount of critical and generative work is helping us as a community question our epistemologies and reflect on alternatives [249]. Next, we discuss specific tools that researchers used to pursue this work.

2.8 Tools for Equitable Processes

> *"For the master's tools will never dismantle the master's house. They may allow us temporarily to beat him at his own game, but they will never enable us to bring about genuine change."* [250] - Audre Lorde, Black feminist lesbian activist and poet

Researchers further their social justice goals throughout many stages of their research projects. Throughout our corpus, we observed that researchers considerations of justice extended beyond a project's topics or outcomes and into the process and methods. The methods researchers chose can be reviewed in Appendix .1.4. To capture why they were chosen, we included a code to capture any "commitments" to social justice made through methodological choices. A commitment occurred any time the project's methodology was explicitly bound to a social justice paradigm. For example, a diary study might include a commitment to reflexivity. This code garnered limited quantitative information as most papers did not write about explicit commitments. Those we did collect showcase the many considerations made throughout a project. These commitments are not tied to qualitative or quantitative practices.

The most frequent commitments were direct engagement with the community (n=11) and self-reflection (n=11). The second most common were those having to do with team roles. These commitments included having researchers participate as members of the community of interest (n=6) and taking on participants as collaborators (n=6) (which may serve to reduce power dynamics (n=3) or empower participants (n=3)). We also saw commitments to engaging with complexity in difficult topics (n=2), making space to support participants and researchers with those difficult topics (n=4), and commitments to care (n=2) throughout the process.

In the remainder of this section, we elevate three tools researchers employ to accomplish such commitments to social justice. Though there are countless tools, we chose three which we believe to be a good starting point for researchers interested in making their process more just. We cover how projects within our corpus use reflexivity, directly reward participants, and employ justice-oriented lenses.

2.8.1 Reflexivity: An Individual Level Tool

Since the 1970s, design scholars have turned towards reflexivity to navigate the *"fragile encounters"* between designers and participants [251]. HCI is embedded within larger systems of power and capital, and reflexivity allows designers to reflect on how these systems shape their research and relationships with participants. 48% (n=59) of papers in the corpus included reflexivity statements in dedicated sections or disparately throughout the paper. In this section, we discuss the information included in these statements and how it enabled researchers to grapple with their individual roles within larger systems of oppression.

63% of the papers that included reflexivity statements discussed **researchers membership** or the (mis)match between authors and participants identities. This involved researchers sharing their race, gender identity, sexual orientation, education status, ability, language, nationality, and class. Consistent with prior work, membership alignment afforded authority to the data collection and analysis process [252]. Authors often pointed to areas where membership was aligned. For example, in their investigation of *"harm, healing, and joy among Black women and femmes on social media,"* Musgrave and colleagues explain their decision to have *"two Black coauthors conduct the focus groups because of their shared identities"* [213]. They share that *"the Black coauthors bring educational expertise and lived experiences to how they approached the study design and analysis"* and that they *"prioritized those over perceived norms and expectations of a "typical" CHI paper or of the white-presenting coauthor."* When membership was not aligned, authors most often acknowledged that as a limitation. For example, Ismail and Kumar share that *"despite our sincerest attempts to understand and portray the* *perspectives of women from the marginalized contexts where our research is located, we acknowledge that our lived realities are starkly different from those of our participants, and we can at best offer a partial perspective,"* [253] and Strengers and colleagues share that *"due to our own cultural positioning as WEIRD (Western, Educated, Industrialized, Rich, and Democratic) society scholars, the scope of our scenarios biased towards studies and interactions we have experience with through our respective research areas, and should be read with this perspective in mind."* [254]. In one instance, however, membership misalignment served as an opportunity to continue learning. Hope and colleagues share that because their team was *"majority white (4 out of 6 co-organizers), college-educated, cis-gender, and heterosexual"*, they undertook personal work to educate themselves, including forming an advisory board to serve as mentors and participating in anti-racist training [210]. They share that this work was *"transformative in helping white members understand and confront the ways racism, oppression, and other forms of white supremacy manifest themselves."* This is an example of what Liang and colleagues refer to as *"personal work"* [252]. Liang and colleagues caution that the HCI community should not rely on reflexivity statements and membership as a shortcut for validating (or invalidating) work with marginalized people. Given the intersectional nature of oppression, it's unlikely that participants' and researchers' identities will match completely. Instead, mismatches in researcher membership can serve as opportunities to investigate and understand oppression in its many forms.

41% of the papers that included reflexivity statements discussed researchers **previous experience with the community**. Prior work has noted the challenges of gaining access to marginalized communities [148, 233], and researchers spoke about the multiple hats they wore to build trust and gain access. This included roles such as researcher/activist, researcher/ally, researcher/community member, researcher/volunteer, and researcher/organizer. Many of the reflexivity statements focused on the community-facing role. For example, Chopra and colleagues describe how one of their co-authors *"lives within the neighborhood, engages with Green South activities and is closely involved with the food growing community, giving the researchers exclusive access, reliability, and convenient recruitment of participants,"* and Berns and colleagues describe how the first authors involvement as a researcher and a participant *"was helpful to gain access to the field. She could, for instance, contact an acquaintance among the community volunteers who suggested some participants for initial interviews"* [255]. Fewer statements discussed the challenges researchers faced in their academic-facing role. In one paper, Leal and colleagues discuss the challenges related to funding structures, citing practices, traditional metrics of success, timelines, and expectations they face from their academic institutions when doing community-oriented work [148]. They see the act of sharing these tensions *"as an act of care -an act of critique because we care and because we want to initiate the change from within."* While this discussion is largely missing from the papers in our corpus, Leal and colleagues demonstrate that sharing the challenges community-oriented researchers face from their academic institutions can highlight structural barriers within the academic community.

The third most popular reflexive element was the authors **political and ethical stances** (observed in 25% of papers with a reflexivity statement). Researchers in our corpus often made strong, explicit commitments. For example, Chopra and colleagues shared that they *"align themselves with social justice and environmental citizen-led movements driven through grassroots and feminist perspectives,"* [256] and Brewer et al. align themselves *"with other design activists who value an explicit orientation to social justice goals"* [179]. At the same time, participants did not always share these commitments. Tseng et al. reflected that their vision for healthcare aides *"may not necessarily map onto those aides may pursue for themselves"* [227], and Battega et al. describe how when they presented digital commons alternatives, they received very little interest from participants [257]. Chopra et al. made strong commitments to environmental and social justice but were disappointed to see that participants *"unwittingly replicate and reproduce some of these more normative ways of imagining food futures,"* including by suggesting that *"sustainability can be achieved through efficiency gains that limitless technological advances and growth can provide"* [256]. Okolo et al. felt conflicted because while they *"view HCI research from a social justice-oriented design practice,"* the community health workers in India with whom they partnered shared sensitive personal data of patients without their consent, raising questions about the role of researchers as allies in culturally unfamiliar contexts [241]. While questions about negotiating value tensions between diverse stakeholders are not new [133], social justice work raises new questions about the ethics of making normative political commitments when working with historically marginalized communities.

2.8.2 Direct Support: A Community Level Tool

In human subjects research, researchers are asked to contend with how their research may positively or negatively impact their participants by institutional internal review boards (IRB) [258]. Beyond the IRB process, harms and benefits produced by the research process are generally not reported. Traditional HCI research has been described as fundamentally extractive [148], and without attention to how research processes produce benefits for participants, we risk reproducing harm.

In our corpus, we looked at how researchers provided benefits to their community partners through direct support. Benefiting participants was front of mind for some researchers: *"the most important component of the initial planning phase was that every interaction we had with residents in the neighborhood had to result in some direct benefit to the residents working with us"* [201]. Overall, this approach was rare. Ninety-four papers (76 percent of the corpus) involved direct work with participants. Out of this subset, less than half (n=39) discussed direct support that participants received from engaging in research, while the remainder did not discuss any type of support. We highlight this data point not to suggest that this work is not happening but rather that it likely does not make it into our research papers. Here, we draw attention to the many ways researchers are directly supporting participants in the hope that it sparks imaginations and provokes conversation.

- **Custom Technology** - Customized technology was the most popular direct support seen in our corpus. Thirteen papers provided custom technology to the participants or partner organizations. While technology development does not necessarily always benefit the participants or partner organizations, we saw examples of technologies that were developed specifically around participant needs and had lasting impacts. For example, Farnham et al. provided *"an online blogging and networking site focused on helping youth connect, collaborate, and take action around local community issues"* [223]. Dimond helped develop an online platform to combat street harassment [180].

- **Financial Compensation** - Twelve papers explicitly discussed financial compensation. Tseng et al. compensated participants $10/hour over the minimum wage *"in recognition of their time and expertise"* [227]. In one case, we saw researchers pay participants who were teachers but not the students who participated. We recommend researchers consider compensation based on the value participants offer to the research process rather than defaulting to minimum standards. One way to do this, for example, is to offer all participants a living wage.

- **Programming**- Nine studies organized or developed programming for participants or community members. For example, Okerlund et al. created programming for a university maker space [209]. Nicholson et al. developed a program to train older adults to become cybersecurity *"guardians"* who could pass knowledge to others in their communities [221]. Kambunga et al. organized six workshops for youth to work toward creating a museum exhibit [259]. Pei and Crooks held drop-in iPad classes and an English as a Second Language class. Their participants *"benefited from practicing English, making social connections digitally, and other online activities"* [197].

- **Organizational Capacity Building** - Six papers worked within social movements or with community organizations to help build capacity for political action or growth. This included establishing symbiotic relationships between community organizations [246], building the capacity to better advocate for themselves [235], building resources and skills to lead or manage grant proposal development [233], and more. Whitney and colleagues, for example, supported their community partners to better advocate for themselves: *"Our HCI knowledge contributed to this struggle for democratic control over technology, but in ways that went beyond design, user studies, or systems building. By analyzing legal and technical documents, we helped coalition members speculate about the functions of the technology and the intention of company and city that animated it. By creating "Slightly Dystopian" demos, we began with the desire to demonstrate latent harms but ended with new insights into the messy, material operation of the streetlights API that proved politically consequential. Finally, our report forged a tool with which coalition members confronted the claims that the City had assembled a coalition supportive of the streetlights, including business owners, technologists, and environmental activists"* [235].

- **Emotional Benefits** - At least[*] five papers reported emotional benefits.

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[*] We did not always collect data on emotional benefits as some emotional benefits were perfunctory and others were not clearly described (i.e., allowing participants the chance to have a voice in technical research)

Bosley and colleagues organized workshops and activities to support healing justice for their participants. They share that the *"practice of Healing Justice gave participants a safe space to discuss the impact of traumas like policing and the ways healing could be integrated into their daily life"* [170].

- **Other Types of Support** - Five papers note other types of support. Those include providing participants feedback on how they did on research measures [260], providing access to personal informatics [205], providing food [253, 261], and creating digital archives on behalf of the community [173]. Ismail and Kumar provided benefits on a case-by-case basis [253]. They note that their participants were *"compensated for their time and care when possible and appropriate as a token of gratitude, such as with chai and snacks, sweets, mobile recharge cards, and transportation costs, but their contributions to our research cannot be measured in material terms."*

Other forms of support that were not included in our corpus but that researchers might consider include sharing the use of physical spaces for meetings, purchasing or sharing access to technology or tools, and creating lasting infrastructure for the community by, for example, writing purchases into grant proposals.

2.8.3 Justice-Oriented Frameworks: A System Level Tool

We collected information on what frameworks authors used and their motivations for choosing them. Frameworks are a valuable tool to decenter dominant ways of thinking and highlight alternative viewpoints. The authors in our corpus used a variety of frameworks to foreground a population, a set of harms, or a specific set of values that may otherwise be marginalized in design work. For example:

> Rankin and Han use Intersectionality *"as a framework for inclusivity* [value]*, positioning Black women gamers* [population] *as legitimate members* [implied harm of recognition] *of the gaming community."* [181]

We highlight this tool because applying a different framework can fundamentally alter a project's process and outcomes. The framing used by Rankin and Han impacts the rest of their research practice, including their study design. Instead of individual interviews or a survey, they organize game events for Black women on campus as a site to gather data. This creates an intentionally inclusive *"social atmosphere for gaming."* They note that *"Because intersectionality invites the inclusion of those who are often silenced, ignored or just invisible, the inclusion of marginalized populations challenges the status quo."* This study design reifies Black women's *"experiences are relevant within the gaming subculture"* [181].

Researchers who used frameworks to **foreground certain populations** often sought to center voices that have been marginalized or excluded from that space. We most frequently saw feminism applied in our corpus. Other frameworks that were used to foreground specific populations included Intersectionality [145], Black Feminism [262], Afrofuturism [263], crip technoscience [264], and more.

Authors who used frameworks to **foreground harmful conditions** often highlighted harms that the HCI community has overlooked. Chen et al. use trauma-informed computing as a framework because there is *"no cohesive accounting of the role of trauma in peoples interactions with technology and what, if anything, those responsible for the design, deployment, and support of digital technologies* *should do to account for the potential effects of trauma"* [248]. In another example, when doing research internationally, Corbett and Loukissas share how they use post-development critique and transnational feminist theory to attend to the *"power inequities between developers and target communities"* [234].

A third set of papers used frameworks to **foreground a set of values or commitments**. These papers discuss how a specific set of values shapes their own positionality or the approach they take. For example, Hope et al. share that, *"our work within the design space of breastfeeding has been guided by the epistemic and emancipatory commitments of feminist HCI, which accounts for situated knowledges and lived experiences and supports innovations that are imbued with sensitivity to the central commitments of feminismagency, fulfillment, identity and the self, equity, empowerment, diversity, and social justice"* [210]. Berns and colleagues use a Community Economies framework to embrace *"interdependence"* and the *"commonality of all beings"* while also highlighting *"marginalized modes of livelihood that co-exist under the umbrella of mainstream economic models"* [255].

Researchers can also use multiple frameworks in the same project. For example, Spiel and colleagues use both interdependence and crip technoscience to understand how technology research considers neurodivergence [126]. They use interdependence to encourage *"researchers to explicitly understand the resulting technological artifacts and implications as political,"* and crip technoscience as a framework for *"centering disabled people as well as making commitments to access, interdependence and disability justice."* Collectively, these examples demonstrate how frameworks can help researchers intentionally center marginalized populations, account for overlooked harms, and provide value commitments that can guide the research process.

2.9 Discussion

In this review, we map the landscape of social justice research in HCI as a basis for our field to reflect, collaborate, strategize, and take collective action. We present the harms and benefits that practitioners investigate (Section 2.6), who they work with (Section 2.6.2), and their reasons for intervening where they do (Section 2.6.3). We also discuss the social levels where researchers can intervene (Section 2.7) and the tools they can use to do so (Section 2.8). In this discussion, we first reflect on how we used these five key considerations to review the field and how HCI researchers can leverage them in future work (2.9.1). We then encourage the HCI community to attend to what is under-researched (2.9.2), make concrete changes to better recognize and reward social justice work (2.9.3), and shift towards pursuing justice rather than responding to injustice (2.9.4). Moving forward, the HCI community can take these steps to address gaps in existing social justice work and move towards more just futures.

2.9.1 Key Considerations for Social Justice HCI

Within our community, it is not always clear what we, as HCI scholars, mean by justice. We found that researchers used justice terms in passing (see our exclusion criteria, Section 2.5.1) and that justice was rarely defined explicitly (only 21 of 124 papers detailed what they meant by justice). While we see this lack of standardization as necessary and useful for intellectual work with a concept that encapsulates a wide range of concerns, topics, and lives, we also want to highlight the key considerations that underlie existing social justice research and can provide scaffolding for future work.

We identified five key considerations that can help researchers frame social justice problems and decide how to approach them. These are by no means an exhaustive list of the considerations of justice but rather a set which we found valuable to work with. There are three key considerations that can help researchers frame problems of justice:

1. harms and benefits
2. who is harmed and who benefits
3. sources of harms and benefits

The taxonomy of harms in Section 2.6 offers language for HCI researchers interested in understanding the lived experiences of injustice, the *harms and benefits* that individuals and communities experience. Looking at *who is harmed and who benefits from that harm* allows us to zoom out to view systems with multiple actors and to contemplate power differentials within those sociotechnical systems. Identifying *sources of harm* (such as research practices, sociotechnical systems, and broad systems of oppression) allows us to consider the various mechanics by which harms and benefits are enacted. These three considerations can support HCI researchers to explore and identify harms in their own work, question why and how people accrue benefits, and interrogate the mechanisms of how these harms come to be. Taken together, these considerations offer a more complete picture of conditions of injustice along with the mechanisms by which they persist.

While the first three considerations help researchers frame and map critical issues, the last two can help researchers decide how to address these issues. There are two key considerations that can help researchers determine a path forward:

4. site/s of intervention

5. tool/s for intervention

In Section 2.7, we build on the work of Patricia Hill Collins to describe three *sites of intervention*. Importantly, one project might take action at all three sites, depending on the tools used. Action can be taken throughout the research process and does not have to be solely represented by the final research outcome. Instead, researchers might work towards justice in the forms of direct support they offer and their everyday interactions with the communities they work with. The set of tools discussed in Section 2.8 provide examples of ways researchers can enact justice through the mundane choices they make throughout their research processes. By thinking about justice as a process, rather than an end goal, researchers can intervene at multiple sites of action over the course of a single project.

Using an article from our corpus, we now present an example of how these five key considerations take form. We hope to illustrate how they can be used in interpreting existing work and setting out on new work. Spiel et al offer a critique of HCI approaches towards ADHD in their paper *"ADHD and Technology Research – Investigated by Neurodivergent Readers"* [126][*]. They share that

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[*] presented at CHI 2022 in a session on "Justice & Equity."

experiences and behavior of folks with ADHD *"are perceived as disruptive to neurotypical standards of behavior,"* and these individuals are rarely invited to the table to co-construct technology. These are *harms of recognition and autonomy* since individuals with ADHD are misrepresented and excluded from design and research. The *people who are harmed* are participants, researchers with ADHD, and potentially the broader public due to biased technology design. Standard HCI research on ADHD benefits the researchers, medical practitioners, and parents, who are all in relative positions of power and are likely to hold and perpetuate dominant ideologies. They may stand to gain long-term career growth (e.g., funding, publication opportunities, etc.) or short-term benefits that stem from power dynamics, such as retaining control or avoiding the discomfort of questioning a non-dominant narrative. The *source of the harms and benefits* is the type of ADHD research that occurs within academic institutions, and that is also the *site of intervention.*[*] Action on the systemic level raises issues of injustice to the broader world of HCI and reifies the experiences of researchers with ADHD on the communal level. For their *tool selection*, they perform a critical and reflective literature review as member researchers in the field in order to problematize past work.

While this paper has a strong social justice component to begin with, the five considerations presented here allow us to look deeper into why these harms exist at all and who benefits from them, to recognize the labor that has not been explicitly stated by the authors, and to imagine alternative sites of action to take on in future work. We offer these considerations as a starting place, not as a full

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[*] Sites of intervention throughout the project might have been broader but unreported

description of what it means to do social justice work in HCI. As eluded to in the opening quote of Section 2.8, new tools and ways of thinking are still needed. We hope that others in our field will continue strategizing and developing tools and techniques that leverage our unique domains.

2.9.2 What's Missing from our Social Justice Conversations?

While conducting this review, we found areas of social justice work in HCI that appeared underdeveloped. We draw attention to critical gaps in the field that require further attention to move forward an agenda of social justice. First, we found a set of harms that are under-researched. Cultural harms, the destruction or imposition of one culture over another [3], have not been fully explored in HCI research. For example, the cultural harm that resulted from building the Dakota Access Pipeline through the Standing Rock Sioux Tribe Indian Reservation is described by Mike Faith, the chairman of the Standing Rock Sioux Tribe, *"Every day the pipeline operates represents a threat to our way of life and an insult to our culture and traditions that have withstood so much."* [3]. Our field has long recognized that computing reproduces colonial systems of power [39, 186, 265], has built on postcolonial lenses to understand the cultural impacts of colonialism [39], and has proposed steps for researchers working towards decolonization [266, 267]. In our corpus, we found that HCI researchers contending with colonialism primarily focused on recognition harms rather than cultural harms. Importantly, colonialism includes the subjugation of knowledge, traditions, languages, and practices

[268–270], and the impact of colonialism cannot be fully understood without unpacking these cultural harms. Anthropologist Arturo Escobar describes resistance to cultural harms as a form of "ontological struggle" and asserts the importance of addressing cultural harms so that we can move towards a pluriverse, a world where many ways of being, knowing, and relating can co-exist [271]. By naming and mapping cultural harms, we can identify places where there are tensions between worlds.

We also found that environmental harms resulting from human interaction with other species and the environment are similarly under-explored in HCI. The negative changes impacting the planet are disproportionately due to human activity, leading to the demise of coral reefs, uncontrolled fires, depletion of animal and plant habitats, and more [151, 272]. While environmental harms are inevitably wrapped up in other forms of harm like increased illness, psychological and emotional distress, and financial and economic burden that constitute important issues of environmental justice, attending to environmental harms specifically allows us to go beyond the human impacts of climate change to understand the damage to the natural world as harmful in itself. Decentering humans is a crucial step to understanding and contending with the Anthropocene [169, 273–275], an unofficial name for the current geological era in which human activity plays a significant role in shaping Earth's climate and ecosystems [276, 277]. By naming and mapping environmental harms, we, as a field, can more effectively advocate for non-human species and ecosystems. To do this work might require perspectives outside HCI, including fields such as environmental sciences, geography, biology, animal studies and more.

Second, the role that intersectionality plays in shaping experiences of harms and benefits has been understudied. Although we did see an increase following calls to attend to intersectionality in HCI [146, 232, 278, 279], few papers engaged with how complex, overlapping identities uniquely contribute to the harms that people experience. The small number of intersectional papers in our corpus could be a result of the standard tools we use as a field. Normative views are often baked into our research design and the tools we use [30, 191, 280]. For instance, single-axis identities are easier to model and generalize since statistical models become more complex when multiple identities are involved. In many studies, those who do not neatly fit into single-axis identities are excluded (this has been voiced by AI ethics scholars [22, 23, 281] as well as accessibility researchers who have observed that less than 1% of articles discuss participants with multiple disabilities [37]). This exclusion perpetuates inequities and does not recognize the wholeness of participants. In contrast, injustice is brought about by complex interactions between multiple factors of identify as well as sociopolitical contexts. Committing to recognizing and studying intersectional identities may require alternative models and strategies for analysis. Further, it may require new recruitment strategies and bringing together intersectional research teams.

Third, we find that the bulk of our attention as a field has been focused on approaching justice at the communal and systemic levels, while there are fewer interventions at the individual level. This may be because researchers are not necessarily identifying individual beliefs as sources of harm (see Section 2.6) or because researchers are not reporting individual-level work in their writing. Researchers in our corpus located harms within sociotechnical systems, processes of design and research, and larger social and political structures of oppression but did not explicitly discuss individual beliefs as a source of harm. While systems of oppression undoubtedly influence individual beliefs, individual beliefs and actions also make up systems of oppression and serve as a unique site of intervention. Furthermore, there may be fewer interventions at the individual level because the field of technology and design research may be less oriented toward shifting personal beliefs and behaviors, instead grouping individuals as "*users*," rather than focusing on complex individual experiences. For example, To and colleagues find that they need to rely on psychology literature when exploring the role that ICTs can play in helping BIPOC individuals cope with racist micro-aggressions [176]. By relying on other fields, such as psychology and education, HCI can more effectively build awareness and support reflection and education processes that change how people think about themselves and each other.

Fourth, we see that HCI research currently does not account for these benefits' role in the continuation of social injustice. Injustice (and the harms and oppression that come with it) exist because people within systems of power stand to benefit from it. Without considering who benefits and how they benefit, we risk placing the burden of change on those who are already burdened. We echo previous calls to "study up" [282] – to study institutions, administrations, and networks that "create the preconditions necessary for specific marginalized and peripheral subcultures to emerge in the first place" [283]. Anthropologists have documented structural barriers to such work, such as gaining access to elite and powerful institutions [282]. In our work, we also faced challenges identifying who benefits and how due to the dearth of language to understand benefits. While Canning and Tombs provide a provisional typology of harm, we found no such typology for benefits [3]. A deeper understanding of the kinds of benefits that powerful groups reap due to systems of power and oppression can shed light on how and why these systems continue.

2.9.3 Recognition for Social Justice Work

Researchers in our corpus moved the needle on social justice issues *despite* operating within unjust systems themselves. As we saw in Section 2.8, common challenges like negotiating membership (mis)alignment, engaging value tensions with participants, and navigating academic institutions are all forms of invisible labor which are not necessarily rewarded by traditional HCI career progressions [148]. This messiness, however, is the day-to-day work of enacting justice. For HCI researchers pursuing social justice work, social justice is not only a research outcome, but can also be a part of their process—much of which goes unseen and unreported. Our field must evolve to make social justice-oriented work sustainable for the researchers who do it. Inspired by Leal and colleagues, we share these tensions *"as an act of care - an act of critique because we care and because we want to initiate the change from within"* [148]. While we do not have the solutions to these critiques, we are hopeful that we can work together to make this research sustainable.

We identified a few opportunities for our research institutions to better support social justice work. First, we hope that HCI can measure research impact not only by the work's contribution to the field, but also its impact on the communities of focus. Reporting direct benefits is not a standard practice in HCI research (as evidence by the dearth of papers reporting on this), but has the potential to provoke conversation about the myriad of ways we can support our community partners. By expanding our field's ideas around research impact and contribution to include direct impact on community members, we can create more spaces for these conversations.

Second, the fast-paced world of technology development does not fit research involving complex, multidimensional social issues. Building equitable research relationships is thorny requiring reflexivity and thoughtfulness. In 2016, Dombrowski et al. recommended the field adopt a commitment to reflexivity and conflict, encouraging designers and researchers to grapple with tensions that arise during the research process [125]. Patricia Hill Collins argues that this work is especially challenging because although most individuals have no problem in recognizing their own victimization, "*they typically fail to see how their thoughts and actions uphold someone else's subordination*" [144]. In our corpus, we found that Hope and colleagues undertook personal reflexive work [252] when they ran into complexity due to not being members of the community they were studying [210]. Their reflexivity allowed them to confront the systems of power that they themselves were part of. These moments of reflexivity, where researchers grapple with conflict, power dynamics, bias, and more, make up the everyday micro-moments where justice is negotiated and enacted. Ultimately, committing to slow, reflexive, and complex work may result in publishing nothing at all. Not all work is appropriate to report on or pursue because it creates more possibility for harm [284][*]. We hope to see recognition of this labor and the development of incentive

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[*] Likewise, the Feminist Data Manifest-No reminds us that refusal *is* a powerful commitment [280]

structures that reward enacting and sharing messy and conflict-ridden processes.

Issues of recognition and reward structures are compounded for researchers from historically marginalized groups. These researchers are more likely to do social justice-oriented work, advocacy, and partake in additional emotional labor [85, 285], all while also facing institutional barriers and epistemic violence [8, 49, 286, 287]. Epistemic violence occurs when contributions made by these marginalized members of the community are silenced, undervalued, erased, and disregarded [49]. Epistemic violence and long-term barriers to access have left historically marginalized voices out of our field and its history. For example, Harrington et al. *"call out the lack of attention and blatant disregard for Black women's contributions to the design canon,"* specifically around design speculation and futuring [109]. Work remains to be done in taking down the walls of the ivory tower so that we can retain and uplift historically marginalized voices [8]. More work still remains in untangling the damage done by a written history and praxis of HCI (and academia more broadly) that has left out, denied access to, and disregarded the labor and worth of historically marginalized thinkers [146, 288].

Doing justice-related work as a researcher with a historically marginalized identity is further complicated by fluctuating institutional politics. In section 2.5.1, we highlight that not all justice-oriented work takes on the label by explicitly discussing social justice. Identifying oneself as a social justice researcher comes with its own risk (as evidenced by recent events [289–293]). This risk impacts who can safely claim justice work in academic writing. Hence, efforts towards social justice is likely to continue under the radar. At the same time, there is something beautiful about our collective efforts happening both under the radar and out in the open.

A commitment to slow work is necessary for social justice contexts, but our inflexible systems of career progress punish researchers who engage in slow, caring work, and the labor it takes to carry it out is often invisible to traditional academic research structures. Without making meaningful changes to our research institutions, we all but guarantee that the technologies we build will perpetuate the harmful systems they are built under [21].

2.9.4 Beyond Responding to Injustice

As our field continues this work, we want to ask what it looks like for HCI work to explicitly pursue justice instead of responding to injustice. We found that much of our corpus focused on a damage-centered view of justice [128], and most papers centered their investigations of justice around the harm people experienced. But what do *just* worlds look like that go beyond responding to harm? How can we be proactive about building those just worlds?

One way to start answering these questions is by listening to historically marginalized communities and privileging their needs and desires. We must continuously ask people who they are and what they dream of, moving beyond aspects of identity towards humanizing communities and developing a real, whole understanding of what it looks like for those communities to self-actualize [128]. The frameworks we highlight in Section 2.8 offer one tool to center the voices and visions of historically marginalized populations. For example, Black Afrofuturism centers the experiences of Black Americans and provides a tool to speculate futures that could have existed had Black existence been historically celebrated [109].

Similarly, crip technoscience critiques medicalized or damage-centered views of disability and instead views ‘disability’ as a part of one’s *“self-determined identity”* [126]. Dreaming is an act of resistance[85], and there are many different ways people have envisioned better futures and articulated their dreams. Part of our work as HCI scholars is to develop the skills and experiences needed to hear and attend to them.

To and Smith et al. highlight that supporting BIPOC flourishing also requires shifting away from design’s tradition of solving problems and moving towards actualizing desires [128]. A growing group of scholars have already argued that the focus on need-finding and problem-solving rests on assumptions of deficit [41, 49] and have called for a shift towards alternative approaches, such as asset-based design [129, 294–296] or design for human flourishing [128]. In the social justice space, the impulse to identify and solve problems allows researchers to react to conditions of injustice but also ultimately reinforces deficit and damage-centered narratives. In authoring this paper, we struggled against replicating these views in our own approach, even as we reported on a body of work that often took this approach to solving problems of injustice. Moving forward, we argue that social justice work must go beyond reacting to problems of injustice to explore, understand, and actualize just futures. To and colleagues reflect that concretely, this shift requires moving the focus of design from meeting baseline needs to identifying and prioritizing *desires*; *“we must seek opportunities for self-actualization"* [128]. Furthermore, moving away from need-finding and problem-solving calls for a fundamental shift in the role of designers from problem-solvers to “facilitators of design” that work to understand and lend expertise in service of the communities they work with [294]. This reframing may challenge our traditional understanding of design; “we must realize that today’s problems hail from yesterday’s “solutions” [128]. Exploring, understanding, and actualizing just futures requires skills and tools to look for, listen, and understand other ways of being in the world, especially when those narratives oppose dominant discourses. Together, we can design the futures we dream of.

2.10 Conclusion

The field of Human-Computer Interaction (HCI) is envisioning and building more socially just futures, yet there is an opportunity to think more deeply about the horizon we are working towards and how we might take steps towards it. In this paper, we conduct a systematic review of 124 papers explicitly pursuing social justice between 2009 and 2022. Through this review, we present a landscape of social justice research in HCI, including the harms and benefits addressed, the approaches researchers use to pursue social justice, and tools that can support thoughtful and equitable research processes. Collectively, these key considerations serve as a useful tool for the HCI community to think about justice-related questions and concerns. We conclude with a reflection on steps the HCI community can take to address gaps in existing social justice work and move towards more just futures.

2.11 Acknowledgements

Thank you to every researcher who is committed to social justice and working to make change. Thank you to our reviewers for embracing the significance of this research and for their thoughtful comments.

This literature review covers only a small portion of this field's incredible conversations and work. We are constantly heartened by reading papers outside our corpus and those in it. To those who are doing the work and are not represented in the corpus: we see you. Keep it up. We hope readers move forward with care for themselves and the communities they work with and within.

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Chapter 3

Interviews on Disability Justice

- **Purpose within Dissertation:** This work is related to both *RQ1: What are common practices for technologists who do justice and equity-based work?* and *RQ2: How do we teach these practices to HCI practitioners new to the space of disability and access?* In this project, I seek to uncover (1) the journeys of individuals with justice orientations, (2) practices that may not be reported in research articles (Chapter 2), and (3) how to bring others into justice oriented thinking.

- **My Role:** Project Lead, with guidance from my doctoral committee and advisor Kathryn Ringland.

- **Other places this text may appear:** This text has not been formally published outside of this document. The process of deciding on the best venue and path forward with participants is ongoing. The document has been sent to participants for member checking, but the text and narrative is likely to change for future publications.

This chapter showcases a series of interviews on disability justice (DJ) and technology creation (especially with respect to accessibility research and HCI). Over the span of 2.5 years, I interviewed 22 people interested in this intersection. Participants included community members, scientists, access researchers, consultants, software developers, graduate students, and professors. The wide range of participants gave me a wide view of the field and how people were bringing DJ into their work and daily lives. It was a great pleasure to speak with so many thinking deeply about the intersection of DJ and technology. Along the way, I took memos and conducted thematic analysis with oversight from Kathryn Ringland. The interviews covered individuals' journeys, practices, teaching, and dreams for the future. Compared to the literature review in Chapter 2, speaking with a smaller group gave me a rich understanding of individuals' daily practices and perspectives. This study was important to the dissertation in several ways:

First, a motivating experience for this dissertation was noticing commonalities in the journeys of other early career accessibility researchers (See Section 1.7.2). Questioning how to do good work, their own positionality, etc. Wrestling with questions and learning more about the space is not something that is usually reported in research articles (with some exceptions including [148, 297]). Instead, friends, colleagues, mentors, etc. informally talk through these ideas. In order to discover the lived experiences and dreams of people thinking about DJ, I needed to speak directly with them.

As shown in the last chapter, some aspects of social justice practice go unreported in research articles. For example, P9 donates money to their cause when using a disabled activist's definition in presentations. I am not arguing that these things should be reported (there is a benefit to quietly subverting capitalist systems), but rather that there is a multitude of ways people enact justice, many of which are unlikely to make it into research articles.

Last, mapping DJ orientations with respect to technology is a fairly new concept for the community. Semi-structured interviews are an appropriate method for gathering the most significant features of an area where relatively little research has been explored thus far. Taking on a study in this format gave me the ability to ask specific questions but also delve deeper into topics I may not have previously considered.

3.1 A Personal History of the Project

Let me begin by saying I feel so lucky to have been able to take part in the conversations from these interviews. In a journal marked 7/11/23 I note: ‘’The best part of my PhD is getting to talk through ideas with people.” In the next two sections I highlight two personal experiences of pursuing this work.

3.1.1 Establishing Pathways for Technologists to Understand Disability Justice

I began this project to learn more about the journeys of other researchers, and understand what doing good work meant in this space. At some points, I wasn’t sure that ‘’good” work in the space of technology and disability was possible. Still, I had continuing conversations with others who were asking themselves questions about how to do good work. For example, in a journal dated 7/11/23, I take note of a friend's second-hand conversation with a budding technologist who:

> *''is super early in thinking about this stuff. [Friend] said she was also wanting a bit of a guide - she was confused about how to learn more when there's so much conflicting info/options."*

The lack of direct discussion about justice in the space of technology was making it difficult to know how to learn more about it. This echoes an issue we ran into while conducting the literature review in the previous chapter. In a journal related to that project, dated 3/11/22, I write: *''How can we teach this work if it's not searchable? what phrases can we search if not social justice?"* Because researchers didn't speak directly about social justice in their work, I was curious about how people learn to do justice-oriented work. Without speaking of it within the community, researchers are likely to mirror my journey: becoming uncomfortable with work that I've done and making slow progress over many years. Is there not a better way? Primarily, it seemed to be all individual work with no defined set of rules for learning. In the journal dated 7/11/23, I note a conversation with a different researcher who verified this concern:

> *''she said that the people who are not going to be super dedicated to starting at the ceiling and figuring this stuff out for themselves also need a way to know the answer. It's interesting to think of the amount of individual grappling someone is able to do being a constraint."*

These themes of researchers wanting to know more but needing a place to start fueled me to look to the journeys of researchers already engaged with this type of thinking.

3.1.2 Discomfort, Vulnerability, Deciding Whether to Continue with This Work

Still, disability justice belongs to the community that created it, and I wrestled with whether to pursue this topic at all. In a journal dated 9/21/22, thinking about the risk of coopting, I even write ‘’is it better for me not to do this at all?” Almost one year later in the 7/11/23 entry, I grapple with whether to publish the work if it is done: *‘’I don’t really want to formally report this in an academic setting because it seems at odds with justice. The systems of academic, publishing, etc. are all really exclusive.”* I’m still not sure that there is a correct answer. But as some participants note in this study, by committing to this work as dissertation research, I was somewhat locked into seeing where it led. I have personally benefitted from doing this work (In 2021 I wrote ‘’*I wish there were other* [technology] *students to talk with* [about DJ concerns]”, and this study allowed me to seek out others to talk to, albeit through an oddly academic avenue). I hope it will be of some use in researcher’s journeys with this topic.

3.2 Introduction

Disabled people, especially those who are BIPOC, Queer, or low SES have been and continue to be marginalized within society. It has already been shown that our research systems replicate and perpetuate harms and biases that exist within society at large. Without understanding and actively working against this ongoing history of social inequity, accessibility researchers are likely to uphold that status quo. For some, engaging with concepts of disability justice (DJ) have been a way to contend with and act toward change [115, 298]. Yet, such cultural and acivist lenses are not always reported in research articles [12]. This work uncovers how DJ orientations impact the approaches, practices, and lives of researchers.

Disability justice is a growing framework and social movement that emphasizes the intersectionality and wholeness of disabled people, and the necessity of building and organizing towards accessible futures collectively with other movements. As opposed to disability rights, it is a movement led by BIPOC and Queer disabled people. As defined by Patty Berne and the Sins Invalid collective in 2015 [4], the ten principles of disability justice are shown in Table 3.1.

The HCI community has recently seen a growing emphasis on social justice. In the last two years alone, we've seen subcommittees, events, and keynotes on social justice and identity-related topics. There has been an increase in the number of papers and workshops on topics related to identity, care, and justice ranging across feminism, disability studies, critical race theory, queer theory, and more (for example [13–20, 22, 109, 115, 128, 249]). In this work, I focus specifically on disability justice in research and education practice. Although strongly interrelated with others, disability justice is a unique subdomain of thought, activism, and community.

Disability justice doesn't offer accessibility researchers ready-made methodologies or practices. Rather, we can look to disabled activists to better understand lived experience within a broader societal context. There are no universally agreed upon socially just approaches, outcomes, topic areas, practices or methods of engagement [*]. Taking on disability justice as a lens allows researchers to contextu-

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[*] This ambiguity can make engaging with topics of identity and critical studies tough for some [31].

Intersectionality	*We do not live single issue lives* Audre Lorde. Ableism, coupled with white supremacy, supported by capitalism, underscored by heteropatriarchy, has rendered the vast majority of the world invalid.
Leadership of the Most Impacted	*We are led by those who most know these systems.* Aurora Levins Morales
Anti-Capitalist Politic	In an economy that sees land and humans as components of profit, we are anti-capitalist by the nature of having non-conforming body/minds.
Commitment to Cross-Movement Organizing	Shifting how social justice movements understand disability and contextualize ableism, disability justice lends itself to politics of alliance.
Recognizing Wholeness	People have inherent worth outside of commodity relations and capitalist notions of productivity. Each person is full of history and life experience.
Sustainability	We pace ourselves, individually and collectively, to be sustained long term. Our embodied experiences guide us toward ongoing justice and liberation.
Commitment to Cross-Disability Solidarity	We honor the insights and participation of all of our community members, knowing that isolation undermines collective liberation.
Interdependence	We meet each other's needs as we build toward liberation, knowing that state solutions inevitably extend into further control over lives.
Collective Access	As brown, black and queer-bodied disabled people we bring flexibility and creative nuance that go beyond able-bodied/minded normativity, to be in community with each other.
Collective Liberation	No body or mind can be left behind - only moving together can we accomplish the revolution we require.

Table 3.1: Principles of Disability Justice as defined by Patty Berne and Sins Invalid Collective. [4]. For more, see [5,6]

alize disability not only in a political, academic, or technological way but also to situate them as whole, real human beings who are impacted by those systems and intersecting identities. In this study, I seek to understand how DJ politic transforms the practices of researchers in our space. In doing so, I hope to showcase some tangible changes that practitioners can make in their daily lives and work.

This is not the first time that highlighting lived experience through a lens outside that of technology has been called for. The value of applying disability studies frameworks to assistive technology research was first discussed in a seminal 2010 paper by Mankoff et al. [46] (There have been external calls to examine the real, lived experiences of people with disabilities with respect to technology since the early 1980s [66, 299, 300], but this was the first formal introduction from within the field of HCI). It wasn't until 9 years later that this introduction was taken up in practice [82, 301]. In the last few years alone, more authors have utilized disability studies as a lens to critically examine the lived social and cultural experiences of disabled people as part of their work [49, 54, 83, 84]. Disability justice is an activist movement intentionally in action outside the academy [*]. When used as a lens for day-to-day life, it can change the way are in community with each other and ourselves [6, 11, 85, 302]

The need for academics to contend with disability justice has been brought to light in disability studies publications [303–305], by individual academics [306, 307], and within HCI publications (via the workshop ''Dreaming Disability Justice in HCI" [115] and its resulting article [298]). These works primarily highlight that higher education and research are in need of justice. We need justice as a lens for

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[*] This is not to say that DJ activists aren't in higher education. There are DJ activists who work in higer ed and more who hold advanced degrees

participants and students, staff, researchers and beyond. A wealth of publications and critiques have been levied against insecurity and harm caused by existing academic research systems within capitalism more broadly [8, 79–81].

In this interview study, I uncover the ways that individuals use disability justice as a personal politic and how it advances their work practices. I focus on the lived experiences of interviewees around teaching (formal or informal), learning, and experiences of technology to draw out considerations for those wishing to apply disability justice to their work.

Section 2 gives a background on the principles of DJ in relation to accessibility research. Section 3 covers the interview methodology. In section 4, I report findings on participant journeys with DJ, conflicts they encounter, common practices, and how they call others in. Section 5 concludes the paper with a discussion of the evolution of accessibility research and performing science.

3.3 Principles of Disability Justice in Relation to Accessibility Research

> *Disability Justice community activists had also observed people adding justice to the word disability without actually enacting any Disability Justice politics or practices* [6]. *Perhaps most troubling, Patty also noticed the framework was being misused and co-opted primarily by white academics and activists who were using Disability Justice as a framework, while the community who created it, the communities that it was meant to sustain and support, had not had a chance to define*

> *its parameters* [5]. -Shayda Kafai, Crip Kinship [143]

Academics have been rightly criticized for coopting disability justice and other social movements more broadly [39, 143, 308]. Yet, to make space for disabled researchers, learners, and educators, we need disability justice in academia[*]. There have been multiple calls for disability justice in higher education [79, 115]. Similarly, there have been many calls for reform of research practices [63, 82, 264, 298, 309, 310] with regard to disabled or otherwise marginalized populations.

In this article, in order to stay in relation and give credit to the origins of disability justice, we frame the paper through the parameters set by Patty Berne and Sins Invalid [4]. Rather than a traditional background, we highlight how common approaches in our field correlate with the principles of disability justice proposed by Patty Berne and the Sins Invalid collective in 2015. This approach gives background on topics necessary to understand disability justice while connecting it to our work.

3.3.1 Intersectionality

Disability cuts across all identities and can occur at any time in life. Kimberly Crenshaw (and earlier the Combahee River collective) illustrate how being both black and a woman creates a unique experience separate from either individual identity [145, 147]. The intersection of multiple identities makes unique experiences, but also an additive, compounding experience of societal harms.

Disability justice has an emphasis on intersectionality in part because prior

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[*] This is discussed further in Section 3.5.3, wherein, despite tensions, researchers employ DJ concepts to improve academic research spaces and their work.

movements (Disability Rights) and scholarship (i.e. Disability Studies) tended towards considering primarily white, educated, and financially established disabled people. Disability Rights made great strides, but the rights established can only be defended in the courts, making them apply only to the few who can escalate issues to courts. Similarly, Disability Studies remains only in academia. Both are spaces that not all people have access to without the means and background necessary to navigate them. An emphasis on intersectionality reminds us that access is intertwined with many other aspects of being.

In recent years, calls within the field of HCI have sounded for researchers to take up intersectionality as a lens of inquiry [146, 232, 311]. Still, researchers have a tendency to only look at single-axis identities [12, 312]. This means we miss out on the wholeness of human experiences. Work on the intersection of race, gender, and ability brings up its own set of issues, critiques, and new design considerations. For two such intersectional considerations of technology see ‘’Amazon Echo and the Aesthetics of Whiteness.” [313]. Another example is Harrington et. al’s recent paper ‘’Its Kind of Like Code-Switching: Black Older Adults Experiences with a Voice Assistant for Health Information Seeking” [314]. With regard to disability alone in accessibility research, it is rare to look at disability in relation to any other aspect of identity [315, 315]. Even with research on only disability as a single axis, we have a tendency to look at only one disability or symptom at a time: less than 1% of papers address those with multiple disabilities [37].

3.3.2 Leadership of those most impacted

Disability Justice emphasizes leadership of the most impacted. Those who are ‘’most impacted” by societal harms have the most lived experiences to learn from and create change, and who have likely been innovating for a long time [85, 264]. Yet, those with those experiences are not likely to be present in the academy due to systemic barriers. There is a history of academics coopting disability justice [143, 308][*].

In accessibility research, there are many ways we dont include perspectives of the most impacted (let alone being led by). Using proxies (parents, educators, etc.) or domain experts instead of community members is increasingly frowned upon but remains a common practice. ‘’Trying on disability” to learn empathy through disability simulation is another still-common practice in AT design although it has been shown ineffective [316]. These approaches are often said to be taken due to the difficulty of recruiting participants [37]. Difficulties in recruiting at the end stages only illuminate that people with disabilities are viewed as the testers, or problem to solve in these instances. With a justice lens, individuals with disabilities are the primary source and are considered to be whole as skilled knowers and makers themselves [264]. When recruiting it has been noted that researchers choose some participants in favor of others based on who will give them the best quality data, even going as far as throwing collected data out in favor of collecting with another [82]. The epistemic injustice of rejecting those who are more impacted but less likely to provide data in a normative way keeps

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[*] This tension is discussed further in Section 3.5.2. It should be noted that in this paper, taking on DJ from an academic lens does not mean creating DJ knowledge: rather that academics need DJ [298]

us from learning valuable ideas. In a just world, those that are most impacted would not only be included in the research, but be the ones doing the research.

3.3.3 Anti-capitalist politics

DJ dictates an anti-capitalist politic because capitalism's value of production above all else is at odds with disability. In capitalism, we measure a persons worth by what they can produce: disabled body/minds are dictated unworthy. Anti-capitalist politic reifies that all bodies have worth regardless of their ability to produce commercial value for others. Capitalist systems often directly harm disabled people. For instance, many disabled people have to decide between marrying the people they love or continuing to be able to support themselves and receive health insurance [317, 318].

For accessibility researchers, policies around insurance dictate what kind of technologies people will have access to. Under capitalism, developing technologies for disabled populations can not be simply about advancing access or even about advancing the state of the art. Our developments rarely make it to market due to the limited market size, with accessibility initiatives often being cut [82]. Assistive technologies that are on the market are often very expensive which is a barrier to use. [319].

Accessibility research tends to focus on providing access to production. For example, assistive technology as a field of study developed out of the vocational rehabilitation of soldiers [72, 75, 299]. Much work is still being done to get access to spaces of work and education, because honestly, we aren't there yet! Still, researchers can consider designing beyond capitalist structures of success for the fullness of life [82, 128].

3.3.4 Cross-movement solidarity

Because disability justice is intersectional, and disability cuts across all identities the pursuit of justice across the board is a necessity. Likewise, other movements must move to include accessibility measures (see [320, 321]). There is existing work ongoing within HCI circles with regard to justice and liberation [12]. Partnering with, being educated on, and actively opposing injustice of others will only help these movements to gain traction within our realm of technology development, and thereby (hopefully) create a more just and equitable digital landscape for us all. While we all work toward the pursuit of new knowledge, academic research has the tendency to silo various fields [63, 111]. Within HCI, our conference and publication systems reinforce that accessibility is a standalone issue unrelated to others. Accessibility tracks and conferences are often siloed even though it is an issue that overlaps with others and benefits all. Seeing access as a single issue unrelated to any other is harmful to our quest for our liberation and that of others.

3.3.5 Recognizing wholeness

Ideas of disability, aging, illness, and more are often presented as loss. While crip grief and loss are unquestionably real, DJ's emphasis on anti-capitalist politic means that each person's value is not tied up in what they can or can't do. Each person is whole.

The wholeness of disabled lives is at odds with design saviorism, which is the view that as designers we can and should rescue or fix what we view as the problems of marginalized communities [39]. This is a common orientation within the space of accessibility research because societal internalized ableism positions disability as a problem to be avoided or fixed. It occurs when well-meaning technologists want to apply a new advancement to do good in the world. This is a deficit-framing of disability [41, 49].

How would looking at people as whole / not in need of solving, change what designers can create, and who we think of as designers? Leah Lakshmi Piepzna-Samarasinha defines Crip Emotional Intelligence and Criptiques as emotional techniques and skills that are culturally specific to people with disabilities. *''Able-bodied people are shameless about really not getting it that disabled people could know things that the abled dont. That we have our own cultures and histories and skills. That there might be something that they could learn from us."* [85]

3.3.6 Sustainability

Similar to criptiques, disabled, ND, chronically ill, and aging people have particular relationships with pacing and time (see crip time [322], spoon theory [323]).

For technologists, taking up sustainability could impact many levels of work. It could refer to sustainability and longevity of the project outcomes themselves [324], avoiding burn out, longevity of community relationships, or considerations for participating in research [52, 186]. It has already been noted that our current research systems do not allow the time and space needed for justice orientations within these areas [12, 111].

3.3.7 Commitment to cross-disability solidarity

Categorizing all disabilities together is not a default, but DJ declares that we can move further by banding together. Collecting different identities fighting for similar causes is a strategic action (see LGBTQIA+ movement). Still, not all communities identify as disabled (See ND and Deaf culture) [6, 126, 325, 326].

HCI focuses on only a few disabilities, primarily those that are visible [37, 45]. Disability is not a monolith. Even those with the same disability will have different experiences, and ones that may change from day to day.

3.3.8 Interdependence

Rather than independence where one is totally self reliant, interdependence is the notion of having agency, but relying on and giving support from and to others. Interdependence allows us to consider individuals as social, and interconnected. DJ activists talk about care webs, access intimacy, and crip doulas. Mia Mingus defines access intimacy as the feeling of being in a space with another person where your access needs are met by default [102, 103]. Stacey Milburn and Leah Lakshmi Piepzna-Samarasinha bring up the ‘’crip doula” as ‘’the more seasoned disabled person who comes and sits with your new crip self and lets you know the hacks you might need, holds space for your feelings, and share” [85].

Historically, much work in assistive technology research has focused on independence as a goal, placing technology as the missing link between a disabled person and being able to interact fully with the world. Bennett et al. published a paper on interdependence as a framework for assistive technology design [84] that illuminates other ways of positioning technology that allows space for interdependence and multiple actors. Other scholars have continued this line of inquiry [107]. Not all work that targets independence is bad, but AT's tendency toward independence rather than agency is often hiding a more sinister bias. As scholar Rua Williams puts it: ''In many projects, technology serves to make institutionalized systems of control, surveillance, and segregation of disabled people more efficient rather than empower increased autonomy for the disabled user."

3.3.9 Collective access

Collective access refers to the way we all share responsibility for and navigate one another's access needs. Navigating multiple access needs can require creativity. Various access needs are sometimes conflicting or competing, and sometimes complementary. For example, live zoom transcriptions could help both HofH or Deaf attendees and those with ADHD. In other cases, access needs can be competing: ''A small room may require that no one use a microphone so as not to overwhelm others, but there may also be people present who find the microphone helpful." [327] DJ dictates that disabled BIPOC people have both the creativity and the directive to conspire toward collective access.

Within accessibility research, one example of creatively negotiating access needs can be found in ''Living Disability Theory: Reflections on Access, Research, and Design" [40] wherein two researchers create an imperfect access plan for saying goodbye and boarding a bus. Within research studies, researchers, collaborators, and participants may all have different and conflicting access needs. In another recent publication, discusses conflicting access issues in HCI research studies and how planning and navigating these spaces takes time [78]. Power dynamics must be taken into account in these decisions.

3.3.10 Collective liberation

This last principle is rooted in the above commitments to pursuing justice across movements and disabilities. No one is left behind, and liberation can only happen as a united front. Technologists should consider the voices present and not present in their studies and designs.

3.4 Methods

This study consisted of 22 semi-structured interviews conducted and analyzed by the first author over the duration of 1.5 years with oversight from the last author. 22 Participants took part in interviews via Zoom, phone call, and instant message. Synchronous interviews lasted an average of 50 minutes.

3.4.1 Interview Structure

The interview consisted of a set of questions relating to (1) their journey with disability justice, (2) how their personal politic has impacted their day-to-day practices in work and life, and (3) how they have taught it to others. Each of these sections included both highs and lows, complex and breezy scenarios. As all participants had varying life experiences and varying knowledge about disability justice, not all questions were relevant to all participants. Instead of a set protocol, a ‘’menu” of questions for each of the three topic spaces was created. The menu evolved throughout the series of interviews.

3.4.2 Participants and Recruitment

Recruitment took place on Twitter, within HCI groups and HCI listservs. Employment in technology-related fields was not required (nor was any employment). Many were researchers across varying fields (technology, informatics, accessibility, education, environmental sciences, health, etc.), but also included scientists, developers, accessibility consultants, program evaluators and community members interested in technology and disability justice. Everyone who responded to the call was somewhere along their own journey with disability justice and was interested in technology design/development. I did not exclude any interviews based on position or domain knowledge but adapted questions to fit their unique perspectives.

Because of the nature of these interviews, I had previously crossed paths with many of the participants in professional contexts and was close friends with others. Of 22 interviewees, only 10 were strangers. The participant pool skews heavily towards those earlier in their careers.

3.4.3 Analysis

An inductive thematic approach was taken. Both memoing and thematic analysis took place throughout and after the duration of the interviews. Interviews were transcribed (if not already text-based) with thematic codes applied to the transcript. A preliminary coding of the first 4 interviews resulted in a revised set of codes that were then applied to the full dataset. These codes included disability identity, career, dreaming, and more. Each code contained a number of quotes, from 13 (Internalized Ableism) to 251 (Tensions). Individual codes were then analyzed for themes.

3.4.4 Positionality and Motivations

I am an olive-skinned, invisibly disabled (usually), PhD student. I'm writing this from a PhD position at an R1 institution. I recognize that DJ was not built for me. Readers, if you don't yet know about disability justice, I urge you to turn to the work of the BIPOC disabled creators who have started and carry the movement [5,6,32,328] before returning here.

I began my work in accessibility as a robotics engineer with a technology-first approach looking for a problem to solve. Since then, I've been on an evolving journey, learning along the way. Every researcher has a distinctly personal journey with their work, yet, there seems to be some overlap in our paths and reflections. Over the years of my Ph.D., I've had many informal conversations with early career researchers who asked similar questions to those I had been asking myself. Like, ''Am I the right person to be doing this work?" and ''How do I balance the extractivity of being a researcher with supporting those I'm working with?" We want to know how to do careful, good, slow research, and so many of us reflect on whether and how to - yet, there is no place I could direct a new researcher to that shows how the previous generation considered these things. The only way is to have a close relationship where you can ask these questions. I became interested in the journies we take in accessibility research, and whether we could make the journey less winding [*].

3.5 Results

In this section, I discuss individuals' journeys with DJ, tensions they find in their work and everyday life, and practices they approach those tensions with. The section ends with participant's dreams for the future.

3.5.1 Finding DJ

Participants were introduced to disability justice in a myriad of ways. Finding DJ seemed to be a winding path, with some introduced to the concept of disability justice directly by name and some slowly seeing injustices and seeking out perspectives online. For example, P3 was introduced to DJ by a research participant. P1's journey describes seeing injustice through personal experiences, witnessing others, and then seeking out information. First, she describes going through the difficulties of requesting accommodations as a site of radical awakening: how the *''entry into like thinking about all this began."* -P1 She then had a heightened awareness ''for other students" going through similar systems. During this time she *''got very interested in and immersed in like reading as much as [she] could."* Personal and closely witnessed experiences of injustice seem to be a common introduction point. P6 describes witnessing how adults failed to engage flexibly with

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[*] Counterventions by Williams and Boyd is a lovely report of one researcher's journey into thinking [297]

her disabled friend as a point that *‘’really radically reshaped how I saw Disability and how I was thinking about Disability. It went from a ’for’ to a ’with”’*

Only a few (P9, P13) were primed through educational settings to think critically about disability and other identities. Some describe social media as a place they came to understand and hear about DJ (P6, 7, 13, 19, 21) after having experiences like P1’s above. Social media has been and continues to be a site of disability activist organizing and community [328]

DJ learning as a journey

Most participants describe long journeys and finding disability justice in more recent times. It was clear that understanding disability justice is an ongoing process for interviewees. Even within the interviews, participants indicate a desire to learn more about what others are doing (P5, P12) and how to grow (P4). Instead of learning all at once, participants viewed their understandings as evolving. For example, P2:

> *“so I think mine is a lifelong journey, right? And I think within that span, I feel like my understanding of Disability Justice is a fairly recent thing. Within the past, I would say five year or less maybe.”* -P2

The DJ principles were published less than 10 years ago, but they represent felt experience. It follows that participants describe their experiences before DJ as part of finding it - even before the term existed.

DJ knowledge and journey did not correspond to career seniority. Participants were primarily early career. P19 also noticed that some students were just starting research but *‘’already kind of came in with a disability justice mindset”* and didn’t have to be *‘’onboarded”* into it. There does not appear to be any specific marker of a hierarchy of journey with DJ thinking. Perhaps this is intentional: P21 indicated that they *‘’prefer for us all to look more sideways instead of up or down.”*

Interpreting past experiences

Finding DJ impacted participants’ interpretation of their past experiences. Some (notably P12) found DJ later in their careers and contended with their own prior work that was potentially not in line with the principles [*]. Others (notably P14, with prior organizing experience) reinterpreted past experiences they had as in line with disability justice: the term just hadn’t existed yet.

Finding DJ also helped participants to interpret and understand their everyday experiences. This is similar to the way learning the term ableism impacted P17 and P18 early on in their journeys with disability justice. P17 says *‘’[P18] was the first person to teach me the word ableism.”* Learning about ableism allowed her to *‘’understand this resistance [to her work]... the fact that not everyone just automatically gets on board [with improving access].”* For P18, learning about ableism was clarifying:

> *‘’oh, there’s a name for this thing that’s been haunting my entire life, right? That puts everything into perspective... there was a lot of emotional upheaval because it was like, oh, this is a real thing ... but it was healing to know that there was like a framework [ableism] around this thing that’s been shaping my entire life.” -P18*

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[*] This has been true for the way I see my own work as well (See Section 3.4.4)

Learning about DJ seems to help individuals act in the world and to interpret their experiences within it. P18 sees DJ as a part of their *''practice in general with, with both advocating for myself and others. And also thinking about the way the world works, how I want to make it better for other people."*

3.5.2 Tensions

Many tensions exist between disability justice and technology design. Tensions are explicitly called out in both the recent DJ in HCI article and the workshop on DJ in HCI [115, 298]. This section builds on previous work exploring those tensions. Participants indicate strongly that disability justice is needed in academia and industry, but also struggle with potentially coopting the movement by bringing it in. While we stand to benefit, implementing DJ within unjust systems that we rely on is sticky and complex. Institutional systems that researchers work within are in direct conflict with disability justice. This section illustrates some of those conflicts.

Co-opting a Movement

Participants indicate discomfort at the possibility of co-opting DJ within the walls of academia. This concern is not unfounded (see Section 3.3's introduction.) There was concern over enacting DJ within various institutional contexts. P9 gives a noteworthy example of a recent event:

> *''a law school is the last place that should be reclaiming disability justice because the whole point is that rights and legislation and laws don't protect everyone"*

Concerns of co-opting related to academic structure's default power dynamics related to community knowledge. P9 continues:

> *'' they had some really good speakers, like they had speakers who are doing the work. But how do we navigate the institutional pressures of? Ok, this is being held by a law school, right? "*-P9.

Indeed, despite best intentions, participants indicate distrust for capitalist academic systems and an inability to uphold DJ principles within them.

> *''I think that academics often will frame work - even if they are trying explicitly not to be extractive - it's still extractive. And even if they're not trying to you know, exploit people, they still, you know, there's still an imbalance of power, there's still an imbalance of compensation, an imbalance of benefit and fame and glory whatever." -P14*

Even for those who have the best intentions, the systems we exist within make DJ principles difficult to carry out. This is true both within and outside of academia.

Engaging with these systems at all, even if trying to make changes, is still within the system, making some participants feel complicit when trying to do good:

> *''until then, I will profit from it and it makes me feel weird, because the only reason why I do is systematic oppression."* -P21

A particular theme related to co-opting justice was authorship. Academia is credit-based. P4 indicates that he has *''to write a paper about it, slap [his] name on it and make progress in [his] degree."* regardless of community need for articles. P8 indicates discomfort at authorship as credit:

> *''I'm really proud of how collaborative the process is and how much the community is involved in my work. So it's a, it's a weird thing of like, only my name goes on my dissertation and it's things that I've done so like taking ownership of that makes me feel a little uncomfortable." -P8*

P9 crystallizes this discomfort with academic authorship as one way that academic work can co-opt community movements. Researchers are in positions of power and are seen as sources of knowledge:

> *''who do we give credit for this idea? Are we giving credit to people who have a lot of educational privilege because they've wrote about it and they've written about it in peer reviewed articles or book chapters or whatever or are we giving credit to the people who had the conversations and really started this and are really living this through their mutual aid, work through their arts practice through everything that they're doing." -P9*

Academics can practice citational justice in order to give credit where it is due. Citations are a way that we signal who is a valued knowledge creator [329]. Still, *''citations don't operate as currency outside of academia in the same way that they do inside."* -P6 and may not do enough. The tendency for academic coopting of community knowledge & not giving credit is an issue of epistemic violence [163, 330, 331]. In the next section, we discuss epistemic tensions.

Epistemic issues

Many tensions exist in how academic systems see knowledge generation and different ways of knowing. First, related to coopting, people outside of the academy are treated as data sources. [*].

> **DJ Principle: Anti-Capitalist Politic** - In an economy that sees land and humans as components of profit, we are anti-capitalist by the nature of having non-conforming body/minds.

Another tension exists between the types of knowledge that are valued by the HCI community and those that are valued within DJ. Last, in contexts where disabled perspectives are valued, there are tensions between the desire for first-hand information from disabled people and their experiences of identity, disclosure, and labor.

Humans as Data: In the last section, I discussed issues of coopting community-created knowledge. One reason this tension is on researchers' minds is due to the extractive nature of human subjects research . Community perceptions and suspicions of academic research are based on institutional legacies. P2 reports their *''institution has a huge history of exploitation in communities."* P16 reports treating people as data as the standard within institutional research:

> *''I actually think that that premise is almost impossible to defend in research, like every single system that you're working then asks you to treat people as a means to an end." -P16*

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[*] This is in stark contrast to the way disabled experiences within the academy are reported: disabled academics are often sidelined [49].

Participants were aware of power dynamics within the community that arise *''just by being a researcher"* -P19. Academic knowledge generation is viewed differently than community-based ways of knowing by the readers, researchers, and the researched. While DJ emphasizes embodied experiences as unique and valuable knowledge via principles of collective access and sustainability, academic knowledge is viewed as scientific, objective and almost sacred. P16 calls this *''professionalization"* and reminds us that *''We all design things to make our lives better,"* and that analogous methods exist outside the academy yet aren't viewed as research or design work: *''parent-teacher associations, like, is that not a design forum that holds a workshop once a week?"*

Valued Knowledge in HCI: The types of knowledge production that are valued are also at odds with disability justice (P2, 3, 12, 16, 21). Contrary to DJ's emphasis on wholeness, P3 reports:

> *''For computer science or engineering students, I found that there's a mindset of like just make the technology, like it's not that user centric, it's just the solution focused mentality." -P3*

Indeed, technology developments for disability tend towards fixing, assimilation, and advancing technology [310]. This technology-first orientation can isolate potential users. P1, P3, P16 each report bringing potential technology developments to users and being met with incredulity at why they would develop those things because they are so expensive as to not be relevant.

Unfortunately, disabled ways of knowing are not always valued:

> *''People somehow think that they know better than you, you know,*

> *even though they're not living your experience, they, they somehow rationalize it in their head." -P7*

Certain kinds of knowledge are seen as requiring a *''formal background"* via study. While P5 already had a neuroscience degree, they report pursuing higher education because their arguments for accessibility weren't being taken seriously in their development job:

> *''it was kind of like, well what do you know, like what background gives you the right to say these kind of things?... that was like my cue to leave industry I wanted to get the kind of authority that I could then leverage to make a difference. And so like getting a higher ed, getting another degree so that way I could say that I had that background" -P5*

Identity, Disclosure & Labor: However, many participants report being looked to as a source for nondisabled people to be educated about disability. P7 also says:

> *''it's hard. It's like, it's, it's like we're giving, we're given an additional job of educating the public. I mean, not only living our difficult life, but educating the public at the same time. And it's, it's a lot."*

It is a good thing that the public and students want to learn from disabled experiences firsthand. Still, there exist issues of labor and disclosure in expecting that knowledge. P0 highlights this conflict between her own experiences of labor and learning: *"I shouldn't have to teach you about ableism as a disabled person, right? But there are a lot of disabled people that you wanna read their firsthand* *experiences."* P11 expresses discomfort around disclosure and the desire to learn from first-hand experiences:

> *''There's some people who you will, you'll never know if they have a invisible disability and they shouldn't be required to disclose it in order to do this work. But then the world is gonna judge them like you don't even know what you're talking about because you don't have these experiences, but maybe they do." -P11*

Issues of disclosure are also complicated as identities are potentially evolving spaces for individuals. P6 reports feelings of stickiness with student's '*hunger*' to learn concepts of disability from a disabled lecturer while she, the lecturer, was on her own complex journey with identity:

> *''they didn't love my answer always, which was its own complicated situation. Like I at the time was saying like, I don't know if I'm disabled. ... I also have really complicated feelings... like, I don't know that me claiming that identity actually gives those students what they want. Like I have a lot of problems with representation as the end of the conversation. Cuz like I think like dis like there are a lot of disabled people who aren't doing Disability Justice. And there are are probably some non-disabled people who are acting in ways that uphold Disability Justice More than folks who are not asked to critically reflect on it" -P5*

Still, P6 recognizes that this feeling of complexity intersecting with issues of representation in academic settings is clear and of specific use for disabled students:

> *''... I also know for me the value I have found in having instructors who look like me.... So like I, I do believe it's valuable ... I want to be that for students now and in the future. But also I don't think it's the end of the conversation." -P6*

Burnout & the Access Champion

People working in this space face the same causes of burnout as any other person. These include making academic career progress (P9, P12), dealing with the pandemic (P0, P8, P9, P11), taking on too much (P9), lack of support (P12), being on call (P20), and meeting high expectations (P11, P18). Yet, anecdotally, everyone working in the space of social justice seems to be more burned out than those in others.

Doing social justice related work [takes extra work], so it follows that people who take this lens seem to be more burned out.

> *''it's been difficult and taxing to be at this intersection of doing a professional job that also has social implications."* -p18, software developer

It's difficult to make the decision to do more in an environment where everyone already seems to be burned out: *''there's two modes, like you're either 110% on or you have to leave and then when you come back, you have to be 110% on again."* -P16, graduate student

Systems are in place to support the established research status quo, but not to support justice-related work. P11 describes those who don't think about justice and use commonly established (but potentially exploitative) research tools as taking *''the path of least resistance."* Our field seems to be reliant on the access champion present throughout this section of writing.

> *''We actually just had a class today where there is a student who brought in like mics for everyone to use because it was like a hybrid class... I felt so bad for him because like, he brought in these mics. He's like, I'm gonna make sure that this is an accessible environment for the folks that are on zoom... I'm pretty sure he missed half the content of the class just because he was paying attention to like moderating."* -p16

Getting others to care: Unfortunately, most people and companies dont do even basic accessibility by default:

> *''it just requires like an individual champion basically You're just kind of limited to people's like personal awareness and sort of rigor for pushing back on a lot of those things. [without them] it doesn't get pushed for and hence it's like lost in like the development."* -P1

Getting others invested is a big part of getting any of the work done. While the value of making access-related change and valuing people as whole beings is clear, getting others on board is a surprisingly difficult task (P1, 4, 8, 11, 12, 13, 16, 17). It is difficult to get people to understand disability in a nuanced way from the get-go, and doing so takes extra labor. P11 has begun working alone because of the negative feelings associated with this additional labor:

> *"It just ended up being like a lot of emotional like thinking when I tried to get people to think about disability and other like I tried to get other people to do it with me so I realized it's just gonna have to be me doing it by myself especially if I wanna maintain the integrity of the project or maintain my sanity and not have to explain XYZ things."*-P11

Instead of onboarding them into DJ-like thinking, P17 describes adapting their strategies to get people to make real changes based on what they care about:

> *"you have to understand people's motivations, their language, you know, something like their love language, right? Like what is it that they value? So if I'm talking to someone whose value is money and status, they are not going to care that it's the right thing to do unless it is tied to money and status."* -P17

These types of arguments might include making money from including people with disabilities, who make up 1/4 of the population (P4,7), and financial or social repercussions for not making things accessible, extending design for disabled people to others (P1, 5, 18), and many more. Overall, they are usually arguments for the worth of people with disabilities in capitalistic terms. Most participants talk about this with a negative valence because it feels bad to do (P11, 13, 16). P16 says they *''always feel really guilty, like couching arguments in terms of like value sets that I actually don't believe in."* P13 indicates disbelief at hearing this approach so often:

> *‘’it’s ridiculous like like the framing of like mental health you could save this much money by like accommodating disability. And it’s like in some spaces you have to say that because we live in capitalism. But like, unless you have to say that, like, why are you saying that?”* -P13

While other participants still acknowledge this is necessary, they describe this feeling as depleting and something that contributes to burnout.

> *‘’it’s actually really hard, like having to do [the] translation work of like, no, well, actually we should care I hate having to make those arguments. Like, I wish there was actually a way to say like, well, don’t you think that every single life has inherent value regardless of how much it produces? Which is like, disability justice fundamentally. And like being in a computer science department, I feel like I, I can almost never just say that piece or I somehow have to couch that piece in like a bunch of other things.”* -P16

Conversely, P17 uses this strategy to get others to care pragmatically based on their energy. Knowing people will have different values, she can use them to conserve energy, rather than depleting it. They continue:

> *‘’So I could either go the hard way and really try to bring them in to caring about other humans or I could point out that you’re gonna get sued and the status of your company is gonna look pretty crappy when you get sued or you can be prevented, right? Like I can just give in and go that route and at times I make the decision based on my energy because you can get very burned out.”* -P17

While it takes effort, it is crucial to remember this translation work is a part of making change and getting buy in. P12 puts the skill of getting others to care beautifully: this translation work is also *‘’camouflaging ... finding a way that my message can be heard. It’s still the same message, but it may be filtered.”* This concept of translation is discussed further in Section 3.5.4.

This is a tension because it is both useful and harmful to get others to care. It is useful for maintaining energy and getting people to make real changes. Still, it feels harmful to allow ableist ideas of worth to continue (P16,18). These tensions are related to ideas of invisible labor, including emotional labor [85, 332, 333], access labor [334–336], and forced intimacy [50, 103].

It’s Personal: This invisible labor is complicated by the fact that we have to do work/maintain face in these scenarios and are often dependent on the people who’s minds we are trying to change for access, pay, and more [333].

> *‘’I think one of the challenges is not just that most people are uninformed and never felt the need to care about this, but also that I have to explain the same shit over and over again and am sick of that now. Like, it bores me and frustrates me to no end, that I have to re-do this over and over and over and over again, while being dependent on the goodwill of people who have no idea how it feels to be dependent on their whim, not even realising that that is the case.”* -P21

Personally identifying with the work you do in a field that by default sees you as a problem to solve can be difficult in many ways. It should come as no surprise that the work we do is personal to us. There can be difficulties in doing scientific research: P13 says for *''the people like who are doing it with lived experience, like its hard it's weird to have to talk about some things in a scientific, scientific way when it's like this is also a personal thing."* But as they also highlight, it can be difficult to just exist in a space:

> *''I think that one of the biggest tensions is, like, talking about disabled folks as if they're, like, not in the room ... like, we're at a conference and you're talking about autistic people there are definitely autistic people in this room and, like, how are they gonna feel if you're just like, I don't know I see a lot of people talking about health conditions or disability in ways that I'm like, this sounds really removed from the fact that like we are in the same space as you."* -P13

The work of making change, whether its creating initiatives or critiquing work often falls on the same individuals or the same group time after time, who are often themselves impacted by the harm they are seeking to change.

> *''nobody's holding them accountable except for me. everyone in the room afterwards will come up to me and thank me for asking the question. But being, you know, a Black queer disabled person and, and use that and a lot of the times with white men, like I'm the person that's catching all the heat. And if you felt this way too, why didn't you speak up if we all knew of, of most of us? This was a problem. Why am I the only one saying something?"* -P20

In P15s organization, they are actively working to support those who do this work by taking on some of the labor:

> *‘’noticed that a lot of DEI work was being spearheaded by administrative folks at the organization and not scientific staff. And that a lot of the burden was kind of being put on, especially women in administrative roles. And so these other scientists and I were like trying to kind of form a coalition to get other scientists more involved in working with that group.”* -P15

Taking on the labor of making change (and even just continuing to work in a field that is counter to your identity) is especially difficult because this is a deeply felt area and often personal: *‘’obviously bringing up social harms is a lot of emotional tax for anyone who’s doing it. Particularly if you are yourself a victim of the thing you’re discussing.” -P18*

This is a tension because we need to be in the space to make a change, but it is difficult to be here if the change hasn’t happened.

Constraints of Research & Development Systems

The previous tensions discussed span domains, but there are several tensions that arise from academic research systems specifically. These include issues like funding and the pace of publication.

> *‘’the incentives of academia are to bring knowledge into the world and that is just not what DJ is about. DJ may involve bringing knowledge into the world but might involve a whole lot of things that aren’t that at all.” -P14*

While academic researchers are sold the notion of autonomy in their research directions, much of it does not come to fruition due to funding and timing.

Funding: Many participants point out difficulties with capitalism in their daily work (P1,2,5,7,9,10,12,14,15,16,17,19), but some research related topics stood out. DJ is specifically anti-capitalist, but research is a business. Because research is a job, researchers are dependent on funding structures for their own livelihoods (P12, 17, 21). Typically funding for access work comes from government grants or corporate initiatives. These organizations have their own incentives for profit:

> *''From a justice standpoint, we are only now ever really pursuing ideas that can be framed in a way that provides value for the funders of the work. -P14 "*

Frankly, sometimes those incentives for profit are just marketing. Several participants were frustrated to find DEI and accessibility being marketed but not actually happening in institutions (P10, 11, 20). P10 notes*''It is so easy to pay lip service to disability, justice and accessibility,* but when looking for the real thing, *it is so much harder to find an institution or even find a culture that brings in that accessibility."* -P10

Issues of funding in academic research dictate what research is done and lock researchers into proposed research. Researchers can't work without funding:

> *'' We're in this double bind of we can't do our work. There's this like meme that says like, oh, I wanted to fight for liberation but we didn't win the grant." -P2*

As discussed in Section 3.5.2, certain types of knowledge are valued in technology development. This value is cyclical. It impacts what gets funded, which impacts what is studied and developed, which impacts what exists: reinforcing the original value. Researchers can only work on what is deemed useful by funding sources, which impacts;

> *‘’funding: like that determines a lot of what gets studied and researched and it’s always tougher to find funding for things that are supposed to be like, yes like accessibility yes to you know, all of that.” -P1*

In order to get funded to do access-related work, participants report having to present disability as lacking:

> *‘’think about all the grants that have been written, like every one of them, I’m doing this for like poor people and blah, blah, blah, blah, blah... it’s harmful, like, like you’re perpetuating biases, you’re perpetuating stereotypes.” -P11*

P11 continues to discuss the downstream impact of framing disability this way: research that only frames people as lacking can only develop certain outcomes: *‘’It means like people have loss of opportunity, they have loss of like ability to like, feel fulfilled and flourish.”*

Research funding typically requires that researchers stay accountable to the proposed work and funding body through milestones, reporting, etc. As demonstrated in Section 3.5.1, researcher perspectives change and evolve throughout the work. Additionally, community-driven research often changes based on community need-finding. P12 indicates relief at not being funded while going through a direction change:

> *‘’I would have been really hosed if I had grant funding that said I had to do a particular thing already for better or worse.”* -P12

Timelines: Academic career tracks and higher education programs all have expected ’normative time.’ For professors, it’s the time to tenure (5-9 years in the USA) and pre-tenure milestones. These require proving productivity through grants received, papers written, service done, etc.

> *‘’This is my last year before tenure. I have everything I just wrote a book. I don’t have any grants. That is enough reason [not to make tenure], even though it doesn’t say I have to have grants. That’s one of one of many things I need to have.” -P12*

Likewise, students are expected to advance through their programs at a certain pace. Student milestones include qualifying exams, theses, defenses, etc. But at the end of the day, P4 notes that for grad students *‘’the absolute objective measure of our program progress is based on like publication”* -P4 . Additionally, academic technology research follows an apprenticeship structure where students are trained by one expert only. This means one person is more or less responsible for grad students getting through the gauntlet of program milestones. Participants report difficulty navigating these relationships because maintaining good relationships with a PI (principal investigator, typically their academic advisor) is necessary for many facets of the job. For instance, P19 notes that DJ is helping them learn to practice self-advocacy for access needs despite PI power dynamics:

> *‘’I’m still learning how to really practice these disability justice facets of rest, of access needs, and advocating for yourself in professional*

> *moments and in situations where there is like a power dynamic between me as a student and others as professors and advisors." -P19*

Publication Pace: For all academic researchers and some industry, there are expectations of routine dissemination (for HCI, usually conference papers). The pace of these expected outcomes is generally set/embodied by technologists who do not do community-oriented work. Several participants indicate not feeling like they are meeting timeline expectations because they meaningfully engage community in their work (P0, P2, P1, P2, P13), or not being able to do the work they would like to due to publishing timelines (P4, P12, P14). P2 notes:

> *''I feel like there's the expectation that you have to like publish at least two papers a year to even like pass. Which is really actually with the work that I'm doing, it's actually impossible, you know, especially when you do really heavily community oriented work. It's a slow process. You need to build rapport with people, you need to take things slowly if you even like want them in the process... community building is a slow process that needs to be done, but that goes against the productive cadence of academic writing and public publications." -P2*

Overall, paper timelines seem to draw researchers away from the community-oriented practices they prefer. All participants aside from P4 indicated that timelines were too fast. P4 didn't note the pace, rather that they were a distraction, slowing the work he wanted to be doing down because *''if I was talking with the right communities, I could jump in right now and develop bespoke solutions... [but] I am incentivized to say, no, I'm not gonna put this out in the world yet. I have* *to write a paper about it."*

P13 notes that taking the necessary time and rushing to publish has downstream effects when working on stigmatized topics or with historically marginalized communities.

> *''I see DJ and traditional academic practices in conflict, but mostly due to the academic pressures, which pose knowledge production within individuals and kind of 'require' a fast-paced 'production' of knowledge, i.e., publications and the like and those might not even be meaningful to the knowledge production that disabled communities need and want* [*]*. So yes, there is tension, but that also means there is a moment where people can make a choice as to where they place their priorities." -P21*

In the following section, I discuss how researchers attempt to prioritize DJ within these imperfect systems.

3.5.3 Practices

Even through the tensions discussed above, participants are guided by disability justice, recognizing that academic research needs DJ in order to make a change. P14 recognizes that *"''academics need the DJ people, but the DJ people don't need academics. I mean, what do academics have to offer DJ spaces?" -P14* P6 also acknowledges this disconnect, but sees that DJ has it right:

> ''Disability Justice is explicitly outside of the institution and intentionally outside of institutions [but] I think Disability Justice folks are

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[*] The idea of communities not necessarily valuing publications that research requires is mirrored by P4 (Section 3.5.2) and p14 at the top of this section

> fucking right. I think they're onto something and so like if I know that there's a better way to do something, I'm not gonna do it the worse way." -P6

P2 struggles with all the tensions and thinks disability justice and academia are an ''*impossible*" combination, *''but certainly we can, we can as researchers be influenced by Disability Justice as our own politics... to be better as researchers."* Likewise, P9 sees a way to *''practice in a way that doesn't co-opt the movement,"* and takes measures not too. Instead, DJ concepts can be used *''to guide how we're doing research and, and scholarship around disability"*

This section illustrates some of those practices for enacting disability justice within research contexts. Herein, participants report various strategies that stem from the disability justice politic and as a result of the tensions discussed above. These strategies are evolving and effortful:

> *''the first strategy is to is to know that there's no assurance that my work is just right, but it's a constant, it's constant work." -P18*

Coping with Burnout

In this section, I discuss the various coping strategies participants had for sustainability due to the tensions and causes of burnout discussed above. These coping strategies go beyond popular self-care activities (though they may include them (P17, P20)) into making difficult decisions about how best to care for oneself.

> **DJ Principle: Sustainability** - We pace ourselves, individually and collectively, to be sustained long-term. Our embodied experiences guide

> us toward ongoing justice and liberation.

Coping with burnout is an act of finding individual sustainability. The guidance of embodied experience (understanding how you feel and the energy you have to give) is distinctly known within disability culture. While the concepts of rest (i.e., Rest as Resistance, Rest as Reparations [337] [*]) and the felt experience of action (i.e., Pleasure Activism [338] [**]) benefit all movements, the experience of disability, chronic illness, neurodiversity, etc. is naturally one of attunement to embodied experience. The principles of disability justice are imbued with this inherent knowledge of self and energy: from sustainability to interdependence to anti-capitalist politic. Participant responses about coping were representative of this guidance. As P16 puts it:

> *''In some ways being sick or like having been sick has given me the attunement to my body to realize that like as long as it like feels good in here, actually, like nothing else matters. there is no deadline, no professional advancement, no external pressure or promise of reward I think at this point that will ever make me compromise what it feels like in my body because, like, it actually doesn't matter."* -P16

P16 goes on to exemplify how the concept of embodied experience continues through anti-capitalist politic, informing how they choose to see their worth in an academic environment.

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[*] Two frameworks originating from Tricia Hersey of the Nap Ministry [337]. Hersey emphasizes taking rest and caring for our bodies as a direct resistance to grind culture which is perpetuated by capitalism and rooted in ongoing histories of colonialism, and white supremacy.

[**] adrienne maree brown explores how working toward change can be filled with joy and desire [338]

> *‘’I think something that I’ve sort of gained over the last couple of years is the ability to, like, just turn on the fuck it switch. And, like, have it be OK... It’s a long internal process of like really decoupling productivity and value for ourselves too... My life doesnt get any better if I meet the paper deadline.”* - P16

This reinterpretation of what matters as an academic researcher and the ‘’*fuck it switch*” was reified by other participants. Participants had to cope by letting go in several ways. These included:

1. Letting go of how they are perceived by their job and trusting in themselves (P12, 21):

   > *‘’what are they going to do... kick me out? That’s fine, I can do other things. And that kind of ... well, knowing that I’m not dependent on this job, allows me a bit to take the liberty to make the most of it while I have it.”* -P21

   > *‘’I know who I am. I know what I’m doing. I’m doing what I’m supposed to be doing and if it doesn’t work out there, fuck them. Like, like I, I will land where I need to land.”* -P12

2. Knowing when not to change things / interpreting situations as not worth the energy or worth less energy based on what they can handle at the time (P11, P14, P17, P19). P17 thinks:

   > *‘’sometimes we expect again, too much from things that have already showed you what they are. So I can always go back to doctor Maya Angelou when someone shows you who they are, believe*

> *them, I'm not going to expect something different from an organization, an atmosphere, a mindset that has shown me what they do."* -P17

Participants changed their work practices to protect their energy. As quoted above, P11 works solo.

If some things won't change with your time, it follows that others will. P17 describes changing career paths to accessibility consulting in order to use energy only to serve people who want to change:

> *''something happened to get their attention or they just care and therefore they want to work with a consultant and want to hear what I have to say, good, bad or indifferent. So that is how one way I positioned myself to not get burned out."* -P17

3. Recognizing that they couldnt change everything as one person (P15, P17, P19, P21). P17 lets go by understanding they may only be one part of someone's change:

   > *"you kind of realize sometimes I can't really, I'm just one person, I can't change the entire world"* -P19

   > *''seeds can get watered and planted and watered by different people at different times. So it's not all on me to be their disability rights advocate the end, they'll never encounter any other situation ever again. I am one evangelist of this that they will hopefully encounter across a swath."* - P17

Likewise, some delegated to others (P15).

4. Relying more broadly on support from communities and finding the right people to work with was a very common strategy (P8, P9, P13, P17, P19) for support with activities of daily living, career mentorship, and commiseration.

> *''You find your tribe, right? ... you know, you vent, you know, and then you move on and then you go back [to the cause of burnout], until you don't feel like going back anymore... and of course capitalism plays a role, right? We need to eat. So sometimes you just have to take it for a little while until you can find a better situation."* -P17

Other strategies included setting boundaries (P9, P14, P15), self check-ins (P15, P17), and even home spa days (P20).

Unfortunately, often there's nothing that can be done while still keeping the things needed to survive under capitalism. Participants indicated needing to wait it out to get access to care and pay, or making career decisions based on access to these things (P12, P14, P17).

Coping itself is not a tension, although taking the time necessary to heal, etc. is not supported by many of our research structures ([286]), but is a way that researchers respond to burnout.

Course Correction

First, possibly due to many of the tensions mentioned above, participants seem ready and willing to be corrected and called out.

> *‘’I’m just prepared to be reminded that I don’t know it all and that it is not perfect what I preferred or willing to understand that despite my best intentions, I might not have acted in a way that was useful (or even turned out to be harmful, ultimately”). -P21*

Participants know they will make mistakes, and report various ways of course correcting. Many report finding a compass that can help them stay on track when they inevitably miss something. This compass can be an internal process (P13, 18), or prompting external feedback from friends (P13) or community members (P0, 10, 17). Internal processes can include formal checks (P5 does a positionality check on bias, motivations, what they will *‘’get out of the research*” and*‘’hopes for how it will influence other populations”* that they can return to throughout the project. P18 reports less formal self-questioning throughout projects on ‘’harms,” *‘’exclusions”* and *‘’knowledge gaps.”* P4 refers to this questioning as a *‘’chronic self awareness.*” P13 imagines people listening to or reading work related to a community they are not a part of:

> *‘’if somebody who I would have interviewed or like, has the health condition of somebody I were to interview or do data, like, collect their data if they were to see it and be like, oh, ick that makes me feel bad, like, I’m not doing my work right. that’s kind of just always been my, like, barometer.”* -P13

External processes include formal research processes like member checking (P4, 10, 19) (similar to P13s barometer but actually checking in with participants before publication), informally touching base with friends and community members (P13, p17), or a combination: P0 reports relying on ‘’*diverse*” and *‘’ongoing feedback”* to ensure she is on the right track. Likewise, P13 finds *‘’creating spaces where like, I can be like gently redirected by people is really helpful.”*

Participants showed a willingness to continuously learn. During P18s guiding self-questioning they know there will be things they aren’t considering. They make a plan: *‘’how can I also go learn more if I do end up making a mistake, if I encounter like an obvious knowledge gap that I have?”* -P18. P12 seeks *‘’exposure across a lot of different sources,”* in order to learn. Many seek exposure by engaging with communities in person and online, and especially by pointing towards the content they create (P0, 5, 12, 13, 16). The next section covers that exposure by being in community with disabled people.

Being in Community with Disabled people

One common habit amongst participants was an emphasis on being in community with disabled people. Whether this was an intentional strategy or just an aspect that connected all who were interested in disability justice interviews, being in community was a strong theme within these interviews. P21 describes this fuzzy boundary between intentional strategy and just a way of being that shapes their work:

> *‘’You asked whether my work differs from colleagues because I take this lens, but I think my work mostly differs from that of colleagues,*

> *because I have made and make different experiences in everyday life, which informs my practices." - P21*

This reflection mirrors their recommendation for people who want to learn more about disability justice:

> ''One of the most important things is that you live with community and hang out with the folks you create technologies for (or better with) and don't proclaim an ignorant 'objective' position that 'just wants to help' (yuck)." -P21

Many participants describe being near disability as part of their journeys to learning about disability justice (P0, P4, P6, P8, P10, P13, P14, P18), and some recommend it as a strategy (P6, P7, P11, P13, P21). Participants describe being near disability as personally liberating or part of their intentionally built lives (P0, P6, P10, P13, P18). P13 reflects on being in community with other ND friends:

> *''in retrospect, like we've all just kind of been accommodating each other like the entire time, right?" -P13*

P18 describes how day-to-day challenges have shifted based on the community they have chosen to surround themselves with:

> *''I think earlier on, in my sort of relationship with disability justice and the mindset of being a disabled person who's alive, I encountered more challenges because I, this is also like a function of not having yet selected the relationships I have now because I was still in the, in the path of growing and learning about what I wanted and valued in*

> *those relationships. And so I was more likely to have ableism in my direct proximity than I am now. So, you know, back, back in the before times, I would get a lot more push back." -P18*

Others (P1, 4, 6) also describe being near disability as a way they began to become keyed in to recognize harms or inequalities:

> *''there are noticeable gaps in experience for both of those, for both like my parents and stuff. So that, like, that definitely got me more in the mindset." -P4*

Participants are clearly changed by being in community with disabled people (whether they themselves identify as disabled or not):

> *''If you don't have like a contingency of people [in your life] who care about disability and you yourself don't have it, you're gonna be like pretty oblivious." -P11*

Still, in Section 3.5.2 we saw tensions that arise from asking people with disabilities to educate us. So, what is the difference between the extractive tendencies of researchers and requiring disabled people to educate us? To me, it seems to be the absence of the researcher role. Without the power dynamics of research, basic relational aspects are available for being in community with others. These include things like care, interdependence, and closeness.

Some participants indicate ethnographic work (where a researcher spends time getting to know a community) as an initial site of learning. Of course, many researchers go into communities to learn about *''the things they're dealing with"*

-P1. Being in community with disabled people helped participants not only to learn about issues and harms but to join forces:

> *''[we] were buds and that helped me to start seeing all the ways in which her teachers and aids and various adults in her life did not treat [her] as a person with autonomy." -P6*

And became a way they were radicalized:

> *''I went from there to help [her] to accomplices with [her] that really radically reshaped how I saw Disability and how I was thinking about Disability. It went from a for to a with." -P6*

This concept of being in community over being there to help is mirrored by P21 at the top of this section. Unfortunately, this is a difficult strategy to enact in practice (P6):

> *''there's a lot that I know and learn from the process of doing, doing life with other disabled people. But also I don't think that that is like a like technique at necessarily because like just go make disabled friends like has complications. Like go be in Disability community spaces and then like if you make friends, yay. But like manufactured friendship is like not my recommendation.'' -P6*

Instead, P6 (and P0, P1, P11, P13, P16) recommend media made by disabled creators as an entry to disability culture. This is discussed in more detail in Section 3.5.4.

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P1, P9, P11, and P21 bring up using financial resources intentionally to support their DJ principles. As P11 puts it: ‘’I try to do it in that way: more monetary and material. I know it’s not enough, but that’s my start.” For P9, a graduate student, this meant contributing to initiatives when using DJ organizer knowledge:

> *‘’When I use resources from disability justice community organizers I do something to recognize them. So like, I very frequently use Talila Lewis’s working definition of ableism* [339] *in my work and whenever I do a presentation that uses it, I donate just a little bit of money to the organization that TL works with: HEARD* [340]*, which works with disabled people who are incarcerated.” -P9*

This approach seems in direct relation to the tension of coopting community knowledge. This is one way for researchers to go beyond only the academic currency of citations and support meaningful work in the community (see Section 3.5.2).

In response to epistemic tensions between community and the researcher, while leveraging academic funding structures, both P11 and P21 talk about *‘’upping the money”* -P11 that goes to participants. P21 wants to make sure the communities they work with *‘’profit from it so to minimise the extractive tendencies that can come with research.”* -P21. If this is an issue for the IRB, P11 emphasizes inconsistency between how we pay participants (1) living wage (she attends university in a high cost-of-living area) and (2) how we pay consultants: *‘’I’m gonna give you as an expert in your own life of experience, like $100 because if you were a* *consultant, you would get $300"*

> **DJ Principle: Leadership of the Most Impacted** - ''We are led by those who most know these systems." -Aurora Levins Morales

P11 and P21 both note the importance of hiring disabled people. For P21, a professor, this means they *''make sure deaf individuals are employed in and lead these projects,"* or they won't do them at all. Many participants indicated that they carefully consider the team that they are building before setting out on any project. For P11, a graduate student who hires research assistants, this meant diverting funds to support students:

> *''I take pockets of money that I know exist and I try to direct them to students who are like low income and disabled and underrepresented... I'll be very targeted in my hiring... I don't really care if they do good work or not. Like part of me, is just like I'm using this as a way to make sure that you have some source of funding." -P11*

Those hoping to enact this practice should note here that simply hiring people is not a perfect system: it requires work and intention. P1, 8, 10, 15 each note issues they have seen or experienced with onboarding into new companies. Some were only brought on for short periods without benefits, didn't have access needs met, and more. These four participants each highlight that cultures, physical spaces, and work systems were not welcoming:

> *''unless there's an actual person struggling to point to it's very hard to get anything done... even when there is an individual person, it takes*

> *months and lots of lots of people advocating to get anything done.”*
> *-P15*

P10 was appreciative but confirmed that access infrastructure is slow:

> *‘’I had to have a captioned phone put in to my office and it took, it took almost three months to, to have put in. The reason it almost took three months is because there were about a half a dozen people involved.*”

Employers were not quick to change. They had to witness struggle instead of asking or preparing ahead of time. As P8 put it: *‘’I feel like that’s the wrong order of going about things.”* This requirement to struggle relates to the labor of expecting disabled people to teach others about their experiences.

Overall, researchers report utilizing funding to support disabled causes. Researchers often determine their budget within grant funding and can plan accordingly for hiring staff and paying participants. These examples show how some researchers can leverage capitalist research systems to support the people from whom knowledge is really coming.

Reporting and Sharing Back

Sharing back to participants : DJ orientations shaped the way participants reported data. For some, this meant sharing reports back to participants for member checking (P4, P10). They did this to thank and keep their participants in the loop: *‘’like, Hey, thanks for participating, here’s how we used your data.*” -P4. When sent prior to publication, researchers can allow participants to shape how they are represented:

> *‘’in journalism, like if you are, if you are being interviewed, oftentimes part of the deal is that the interviewee gets kind of like veto power over how they’re represented.”* -P4

and allows researchers to make sure they are on the right track:

> *‘’give them a sample of, of what you, of all the codes that you come up with and say, all right, y’all, is this something that - do you agree with this? Do you disagree with this? Tell me how wrong I am. I invite them to tell you how wrong you are or when you miss the boat.” -P10*

This reporting is not standard and appears to be a way for researchers to address power dynamics in representation.

Specialized Reporting: P12, P13, and P17 are cognizant of reporting to different audiences. The translation work done by participants contributes to burnout for the reasons listed in 3.5.2. Yet, it is also a skill participants develop. Both P17 and P12 indicated developing strategies for conserving energy and getting DJ-oriented research or accessibility practices into spaces it may not otherwise be in. In a way, the ability to translate is an act of advocacy.

Citations: P6, P9, and P16 both highlight the importance of acknowledging the troubling history of coopting (see Section 3.5.2) community knowledge, and acting against it through their citations:

> *‘’if I am writing a lineage of this knowledge, I always make sure that it doesn’t go through academia.” -P6*

P9 urges people thinking about disability justice to remember and honor that the movement started in conflict with how primarily white scholars and activists approached disability in the disability rights movement.

> *''if you're talking about disability justice and you're not citing sins invalid* [6]*, you're not citing Nishida* [341]*, you're not citing the, the people who created this movement. Like that's a huge problem. If you're only citing like white scholars that are talking about disability justice in these, you know, fancy flouncy terms. That's a problem." -P9*

3.5.4 Teaching

There is no standard way to onboard others into DJ thinking. As we saw in Section 3.5.1, finding disability justice was a journey for many, including P2:

> *''the hard part is I, for me personally, it was a long journey to get to a space where I, I incorporate Disability Justice as part of my own like personal ethic. But for someone who has never had that groundwork, it's almost like it's a lifelong process. I think making it easier to a door as a first entry is super important." -P2*

Those who already work on disability specifically, are likely not taking a disability justice-oriented lens. P19 expected *''accessibility research to be a safe space."* But through working in the field has seen that *''it's not the case. Just because someone researches an area, that doesn't mean that they actually do this in real life." -P19* Similarly, P18 notes:

> *‘’I think that there are plenty of people who professionally work in accessibility but haven’t interrogated a ableism in themselves at all. And that’s a very fascinating and frustrating. What to me is like a conflation of obvious problems.”* -P18

Taking a disability justice-oriented lens can mean a world of difference.

Why Teach to Technologists:

Teaching DJ orientations to technologists matters because technologists build worlds. P14 notes:

> *‘’We have so much power over people’s experience of the world and the spaces they inhabit. Every engineer absolutely needs to understand what that means.” -P14*

Indeed, the technologies we build are used in real contexts. P1 notes that a DJ lens should *‘’be incorporated”* because:

> *‘’[tech] dictates so much of like how people receive care or what type or like just basic needs and how like they can go about like doing things and just survive.” -P1*

P16 agrees that *‘’engineers and computer scientists and people making this stuff have so much power.”* and the technologies we build are much more than *‘’an intellectual exercise.”* -P16

A Way to Challenge Dominant Perspectives: Yet, technologists don’t generally have any social, critical, or qualitative training (P6, P9, P14, P19).

Existing issues multiply if the people building our worlds are only focused on advancement:

> *‘’I think a lot of the work that gets people really excited is just computer science stuff - stuff’s faster, the algorithm’s better, the system’s bigger... Say you had barriers? Now your system’s faster and bigger so now you got bigger and faster barriers ... it gets out of hand fast”*
> *-P14*

Disability justice functions as a mechanism for critical interrogation of dominant perspectives. For some researchers, it helps them stay grounded. Just because something is viewed as technological progress, or it involves disability doesn’t mean its good. P6 reminds us of the importance of being critical through historically dominant ways of thinking:

> *‘’eugenics was not a fringe movement. Eugenics was the science, it was the popular scientific way of thinking. It was what people thought was right and it did immeasurable harm to disabled people. So you need to know this, you need to know this as scientists wanting to work with disabled people, that you are not walking into a history without harm. That you are walking into a history where even the prevailing winds of how to do science with and about disability can do significant harm. You have to critically interrogate what you’re doing and why.”*
> *-P6*

Taking a disability justice lens to technology development changes the way we see technology itself.

A way to change the way we understand the world: Participants indicated that disability justice changed the way they saw things both in their prior work and in their daily lives (P2, 4, 9, 11, 14, 16, 18):

> *‘’people that are a little bit more informed by like disability have a really different set of values around like why we build shit, like how we critique shit, like the kinds of human computer interactions that we want. you’re no longer approaching, like, with awe or with pity. You just can’t after going through a disability, justice education.” -p16*

Value of onboarding others: In the end, calling people into the fold of DJ matters because we need more people thinking critically and making change. Holding steadfast to concepts of justice is hard work. And doing it while working against those who don’t yet understand is more difficult. As P12 puts it: ‘’*it’s an uphill battle if we don’t onboard, the people that aren’t aware of ableism and things like that.”*

It’s necessary to teach DJ *because* the work is hard. P17 bringing people into DJ thinking because ‘’*if someone really understands the value of this, they’re gonna, they’re gonna be OK with it being hard.”* -P17

How DJ is Taught

Participants indicated several methods used for *‘’bringing others into the fold”* -P14.

The most common way that they taught and recommended newcomers enter into the world of disability justice was by engaging with disabled cultural artifacts (P0,6,7,9,14,15,16,18,20) [85].

> *‘’The thing that I do think is really accessible and really doable is pick the media that you like to be on. Are you on TikTok? Are you on Twitter? Are you on YouTube? Are you on Facebook? Do you really like books? Like they’re starting to also be good TV and movies and just put Disability in your main, in your content feed.” -P6*

This relates to the practice of being in community (see Section 3.5.3). Some specify specific media or media creators for people to seek out (i.e., Sins Invalid [342] -P9, Crip Camp [343] -P17, Molly Burke [344] -P0, Imani Barbari [345] -P15). Not all of these are explicitly DJ oriented creators, but engaging with disability culture seems to be the first step advised by many. Having a starting point can help get learners started because while *‘’there’s really good stuff out there on social media. There’s also a lot of misinformation.”* -P20. P18 highlights the existing cultural labor that those interested can tune in to for justice-specific knowledge:

> *‘’there are plenty of disabled people who, who dedicate their entire life work and platform to doing this kind of education.” -P18*

No formalized media list was mentioned, but both P16 and P19 indicated an interest in providing a starting *‘’like packet I could be like: here do this first.”* -P16. [*].

Another popular way of teaching is having *‘’uncomfortable conversations”* -P15 (P7,12,15,16,18,20). These conversations happen both as processing with *‘’trusted people”* -P0 (P0, P12, 13, 15, 17), and ad hoc (P7,12,18). Ad hoc conversations happen in the moment when participants call out others. For example, this could

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[*] I would recommend ”Access is Love” reading list [32] and ”Black Disability Justice Syllabus” [34]

be as small as using offensive language: *‘’unless somebody points it out to you, you know, you don’t really notice it.”* -P7. P7 elaborates on why these small conversations are important:

> *‘’any chance that you get to, to point it out, I mean, not, not in an aggressive way, like you’re doing this wrong, you know, you’re trampling on my rights, you know, just say, Hey, by the way, have you ever thought about this? ... any little chance that we get to kind of bring it to someone’s tension, we should do it. You know, maybe after the 50th time they hear it, maybe they’ll start thinking, oh yeah, those other people do exist.” -P7*

P12 highlights that personal conversations are a better way of learning than formal critique or callouts online *‘’so that people can start to see [each other] as human and not just an adversary.”* -P12

Several participants highlight fostering curiosity and critique (P0, 5, 10, 18). P10 tries to help students think *‘’more critically about the technology and the tools and the services we use every day.”* For example, P5 asks people to question *‘’the reasons why something is created the way it is and like whose interests being represented in the way that we structure technology and our society at large.”* -P5

P18 values fostering curiosity because it is *‘’a self-generating path of discovery for them.”*

These strategies tend toward preliminary exploration and openness rather than explicitly naming DJ concepts off of the bat. This was echoed by P14 who uses ‘’ambiguity” to teach. First, introducing *‘’new ideas through demonstration,* *through explanation"* (ie *''I want you to just not think about people's productivity right now."* rather than naming anti-capitalist politics). *''Then, [later] maybe you give it a name and connect it." -P14.*

Last, importantly to calling others in, P5 reminds us that extra support may be needed when learning about DJ-related issues:

> *''if you're trying to shift somebody's assumptions about the world or like talking about these topics that often have a lot of like morality and emotion tied to them."* -P5

3.6 Dreams for the future

Disability justice changes what is possible.

> *''it follows an anti capitalist approach which is: OK, if our bodies are whole and we're not just supposed to just produce stuff, then what are our bodies for? And I think that that's the real liberating part of disability justice. It's streaming towards a future that is filled with things like joy and a sense of belonging and togetherness and things that you don't get ... viewing disability from many other places. And to me, that's the justice in it really. People who live with disability often the injustice that they face is a loss of beautiful futures and disability justice kind of seeks to like, restore that."* -P14

> **DJ Principle: Recognizing Wholeness** - People have inherent worth outside of commodity relations and capitalist notions of productivity. Each person is full of history and life experience.

Leah Lakshmi Piepzna-Samarasinha [85] and other DJ activists position dreaming as an act of disabled resistance, because our futures are often taken from us. Some interviewees discuss their various dreams for the future, both personally and institutionally. On a personal level, P14 says: *''If I really want to pursue disability justice, shouldn't I live it also for myself?"* -p14

Dreaming is a motivator to continue working toward change:

> *''if I didn't fundamentally believe that a better world was possible, there's no point to me doing any of this. That's all I have at the bottom of all of it is that I believe that we can create and we all do deserve better."* -P18

Many of the dreams were around institutional and societal change:

> *''I do wish we had somehow taken a better stance of again, this idea of community and this idea of diversity sooner so that it was more ingrained."* -P17

It was clear that institutional change is desired. Our traditional systems that don't value concepts of disability justice put researchers on the wrong track by default. For example, P19 hopes researchers will contend with how they are *''complicit in imperialism and colonialization."* P11 calls this status quo, where all actions are imbued with ableism, colonialism, capitalism, etc., by default the ''path of least resistance" for those who dont ''think through these things in their day-to-day." On another institutional level, many dream of better practices around funding (P2, 12, 14, 15, 16): *''I think maybe there needs to be more transparency* *around that. Like across the board, right? Yeah. And where this money's coming from."* -P2

Dreams for these changes were both long and short-term. Short-term dreams tended to revolve around making small changes. P 15 says *''if I could overhaul society, I would"* but indicates concern for additional difficulty and unrest for the communities in question that it would take to get there, and prioritizes *''incremental progress"* to systems for impact. Likewise P9 acknowledges that

> *''even while we change the system, we need to make the system better for the people that are already here." -P9*

Participants wanted access to spaces (P18, 20), access to basic needs (P15), epistemic justice (P16, 19, 21), all by default. As P20 puts it, *''we need to figure out how we can create something where again, nobody has to be taught resiliency and, and coping mechanisms and things like that."*

Participants dreamed that they wouldn't have to stand in for people who should be there by default:

> *''the hope for me, at least right now, is that we have the option to make deaf talent more recognized to the point where (again, in this small context), we end up having deaf researchers themselves having the standing and position to advise others and themselves."* P21

Others dream about finding community with each other (P4, 5,11,12,17):

> ''Man, we should all be in a group together because I feel like, I mean, that's probably it, we probably need that communityThere's nobody really to go to, to answer this stuff." -P12

Regardless of the standard power structures that keep them separate: *''I can't like take a participant out for a cup of coffee and write a thank you note at the end, right? Wish I could."* -P16

Some are around how we are allowed to spend time, taking a step back from work both to reflect and do whatever we want. For reflection, P1 wishes it was possible to say: *''we're gonna take a timeout to, or like make sure that we don't, we support this kind of perspective in our work."* -P1

More broadly, participants want for both themselves and disabled people in general to be able to do whatever they want: *''the ultimate goal is about working less, it's always about working less but people with disabilities, working less so that they can do what they want with their time instead."* -P14

Participants dream of futures without the idea of work at all, being able to pursue whatever they like instead of ''*trying to be productive, trying to add value to something."*-P14. As P18 puts it: *''we all deserve to be lounging by the pool, eating fruit rather than working."*

Overall, participants were hopeful for change, even as some of them saw it changing before their eyes. Two participants indicated they are hopeful because they already see change happening, especially from a newer generation (P13, P21):

> *''The students, honestly, give me a lot of hope. Students mostly … get it." -P21*
>
> *''And so I think that like, one of the things that makes me hopeful is that like these conversations are happening. And like, I, I am being made more aware of these things. And also like, I think the like newer*

> *generation of scholars is like willing to have those hard conversations."*
> *-P13*

In the end, our futures are (in part) up to us. P14 dreams beyond disability justice and encourages the researchers who work in our field to figure out what's next collectively:

> *''I think we absolutely must explore what is next? What are the new ways we need to think about ourselves and the world around us? We should reflect on you know, the real mission goal, whatever of DJ and like take a step back. Is it working? Are we really moving towards justice? What can we do now? What are new ways to think? What are the next things to do? So, yeah, I think that something has yet to be thought that we must think and that thing I am looking forward to."*
> -P14

3.7 Discussion

In these results we saw the incompatibilities of applying a DJ mindset within technology spaces, common practices for dealing with them, and the importance of doing so.

As discussed in Sections 3.5.2 and 3.3, DJ is a movement that originated and intentionally remains outside of the academy. Academic disciplines like disability studies are focused on lived experience but still exist within the confines of the academic domain, bearing markings of white and well-off scholars. Disability justice emphasizes leadership of the most impacted. Those who are most impacted are not present in the academy due to the systemic barriers and marginalization that DJ seeks to rectify. DJ creators have been rightfully bothered by this [308, ?kafai_crip_nodate]

> ‘’Why Disability Justice in academia? As one of the founders of DJ, it’s very sad that DJ has been highjacked from community scholars who are/were people with disabilities that are queer, transgender, straight and poor people. Now a class on DJ will be taught @ UCLA Winter quarter.” - Tweet by Leroy Moore @kriphopnation, 09 December 2022

Taking on research from a DJ lens does not mean creating DJ knowledge. In Section 3.5.1, we saw that participants’ journeys did not usually include learning about DJ through academic education. Instead, it was through engaging with disabled activist culture and being in community with disabled people (See section 3.5.3). Neither did participants recommend newcomers to learn through academic settings. As stated by P14, DJ does not need academics. This is mirrored by disability scholar Ada Hubrig:

> ‘’The activists and organizers taking on meaningful disability justice work in their own contexts and communities dont need a bunch of academics with fancy titles to theorize disability justice for them: disability justice came from disabled QTBIPOC folks.” -Ada Hubrig [303]

Yet, the absence of the most impacted within our community emphasizes some of the change needed within our systems. As indicated in the intro to Section

3.5.3, the space we do research in needs change, and it pushes those same folks out. Disability Justice may be '*incompatible*' (P2) with research's primary goal of ''*bringing knowledge into the world"* (P14), but it gives us a way to think about making steps toward that change. As Rua M. Williams puts it:

> ''Academia is poised to coopt #DisabilityJustice. But we are poised to infiltrate and corrupt academia."

-Tweet by Rua M. Williams[307]

3.7.1 Beyond Basic Access

All technology development and research in the space of accessibility is concerned with the wellbeing of disabled people. DJ orientations seem to cause practitioners to take a step further. While accessibility researchers have been emphasizing the value of perspectives directly from disabled individuals (rather than proxies) [37], developers are sure to get those perspectives by having disabled participants. DJ oriented practitioners go one step further, making sure disabled, Deaf, ND, or chronically ill people lead the projects about them; See Section $$$ (see collective access principle).

Some participants put this extra step into words. Rather than *''productivity"*, P19 sees DJ orientated accessibility research as *''thinking about joy, activism, pleasure."* and able to involve *''conversations about systematic ableism."* P6 sees it as *''a shift toward the radical."* In thinking about DJ orientations versus traditional access reasoning, P9 highlights the *''distinction between solidarity and charity"*.

Historically, accessibility research is concerned with independence and creating access in order to get disabled people in the door at all. DJ gives us a way to dream deeper. In the words of DJ activists and community builders Leah Lakshmi Piepzna-Samarasinha and Stacey Milbern:

> *‘’My wild dreaming has me longing to go deeper than just getting basic access. As my friend and comrade Stacey Milbern recently posted on Facebook, Sometimes I feel impatient about how much ableism has forced us to emphasize accessibility . . . [But access] is only the first step in movement building. People talk about access as the outcome, not the process as if having spaces be accessible is enough to get us all free. Disabled people are so much more than our access needs; we cant have a movement without safety and access, and yet there is so much more still waiting for us collectively once we build this skillset of negotiating access needs with each other.”* -Leah Lakshmi Piepzna-Samarasinha and Stacey Milbern

Shifting Ideologies

Many participants were early in their careers. DJ knowledge is not relative to seniority. Participants were at all different stages of thinking with disability justice. Unlike other domains, seniority as a researcher didn’t dictate whether someone was further along in thinking about justice than another. Rather, many early career folks were stirringly discerning and introspective with some later career folks at earlier stages of inquiry. Everyone was still eager to learn and continue their journeys. P16 notices this when onboarding new researchers in Section 3.5.1. In

Image Description:*A line graph with three lines labeled racism, sexism, ableism. Use of the word the racism picks up in 1940 and ends about 5 times higher than sexism. Use of the word sexism picks up around 1970 and ends about 4 times higher than ableism, which ends in barely a blip in comparison to the others after picking up around 2015.*

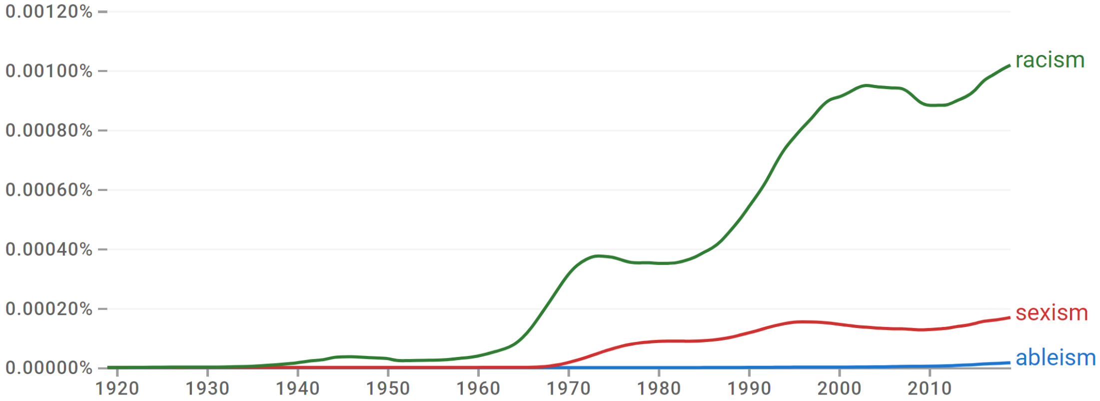

Figure 3.1: Google Ngram viewer of the use of the words racism, sexism, and Ableism in books over time from 1920 to 2019.

Section 3.6 P13 and P21 both note that students give them hope.

These ideas are developing with a newer generation of ideology, just as accessibility research continues to consider new horizons [346]. This reflects a broader shifting in language and ideology in the world. For example, during this interview series I discovered many participants hadn't heard of ableism until about 2010. It turns out the word wasn't used much until then (see the Google NGram chart in Figure 3.1). The principles of DJ were only published in 2015. DJ ideas are still evolving and making their way through our wider culture. This is a reminder that our cultural knowledge and vocabulary is continuously evolving. Even the findings herein represent only one snapshot in time.

Journeys were marked by inevitable missteps, and researchers had strategies for approaching mistakes (Section 3.5.3). I hope that readers will reflect on their own journeys with care. We will all inevitably make mistakes in our journeys - it's a part of learning, and it is always possible to move forward and do better. For more resources on course correction see: (1) Mia Mingus shares thoughts on apologizing, outlining the four parts of accountability: self-reflection, apology, repair, and changed behavior [347]. (2) Williams et al. for an overview of one accessibility researcher's journey through a reparative lens. Includes a rubric for evaluating past work [297].

3.7.2 Performing Research

Many of the tensions discussed had to do with the inflexibilities of research systems. The ability to course correct and change (Section 3.5.3) is made difficult by funding structures (Section 3.5.2), and the permanence of published articles (See 3.5.3). Knowledge created by non-researchers can be coopted (Section 3.5.2), and is viewed as different than researcher-created knowledge (Section 3.5.2).

Overall, researchers were encouraged to perform scientific objectivity, which may not actually reflect how knowledge is generated. This is true of this study, where I interview 22 participants, half of which I know. Rather than conversations or collective reasoning about shared interests and struggles, I remained an objective observer in order to maintain scientific integrity and get publishable results. P16 points this out during our interview:

> *''Even us talking... I'd love to hear, you know, like your thoughts too. I understand, like, [you would be] influencing my opinion... no longer impartial. Like, I get the reasons why there's sort of this like fake scientific method behind it, but why... who is the script for?" -P16*

Also within this study, participants were hungry for a community of other people who were struggling with similar questions. While the IRB is a good system of checks and balances, it can still be a part of this scientific performance. Due to agreements of anonymity in the IRB process, I cannot ethically connect them, although many indicated wanting to know and be in community with one another (See Section 3.5.3).

This scientific performativity, or "professionalization" of knowing may be necessary for current publishing standards and scientific methods, but some of the practices we are beholden to can cause real harm. These harms include coopting and epistemic injustices (see Section 3.5.2 and Section 3.5.2) when people are seen as data rather than agents with their own lived experiences and ways of knowing. In Section 3.5.2 we see that talking about people as data or as being problems to solve also impacts those researchers who are in the room listening. In doing so, we risk driving away the people we claim to want in the room (Sections 3.5.2, 3.5.2, 3.5.3).

3.8 Conclusion

In this work, I cover the principles of disability justice in relation to accessibility research (Section 3.3). This series of interviews contributes common concerns and practices relevant to the intersection of technology and disability justice, and reasons to teach DJ orientations to technologists 3.5.4.

Section 3.5.1 shows the various journeys for individuals changing their perspectives through finding DJ. These journeys are reflected in the shifting ideologies of the field more broadly (Section 3.7.1). While technology development and research is still incompatible with DJ (Section 3.5.2), we are finding ways to make slow changes, to support each other within these broken systems (Section 3.5.3). While existing within these systems may not be sustainable long term (Section 3.5.2), researchers are making real change in these systems through their everyday actions, and the tides do seem to be slowly turning.

To me, ableism has been a part of the common vernacular as long as I have been doing this work: I had no idea it was new, because it seemed to be a standard part of understanding societal aspects of disability and approaching accessibility research. My hope for the principles of DJ is that we will continue to recognize them as rooted epistemologically in the communities they came from, but that they become commonplace, standard, obvious. It should not need to be radical to recognize people as whole, to value more than their productivity. I hope that technology developers and researchers will use the ideas and strategies herein to work towards that future.

Chapter 4

DREEM

- **Purpose within Dissertation:** This work is related to *RQ2: How do we teach these practices to HCI practitioners new to the space of disability and access?* In this project, we develop one practical method for teaching cultural knowledge. Using DREEM, those who are unfamiliar with disabled communities can develop a nuanced understanding of them before engaging with them in a research context.
- **My Role:** Project lead, worked collaboratively with Jared Duval, and Kathryn Ringland starting in 2019 with 5 years of data collection in various groups led/taught by each of us.
- **Other places this text may appear**: This text has been submitted to ASSETS '24 with the title *DREEM: Moving from Empathy to Enculturation in Disability-Related Human-Centered Design.* It is currently under review. The project has been previously submitted (and rejected) under various names at various conferences. It was shown in several CHI workshops including *Social Media as a Design and Research Site in HCI: Mapping Out*

> *Opportunities and Envisioning Future Uses* and again in *Dreaming Disability Justice in HCI.*

In human centered design, empathy is critical to help designers find relevant and helpful directions for designs and problems to solve. DREEM (Disability Related Empathy from Existing Media) is a method developed to stand in for traditional empathy-building techniques for disabled populations, like disability simulations, that often miss the mark. In a disability simulation, a designer tries on a disability for a given time by using a mobility aid, a blindfold, etc. These exercises position disabled people as inherently lacking (deficit view (See Section 2.9.4)). They continue to be common practice, although they have been shown to foster pity and fear in place of empathy [316]. In a way, ‘’feeling bad for” is a half-cooked form of empathy - but it doesn’t seem to get designers to think about meaningful ideas for the disabled community. What does it mean that the tools designers use foster a deficit view of disabled body/minds by default?

Instead of imagining a disabled person, trying on disability, or asking a disabled friend to divulge personal information, DREEM asks designers to engage with cultural artifacts created by people with disabilities. In the context of this dissertation on justice, the contribution feels almost too straightforward: taking a justice orientation will require designers to listen to disabled people, and to be in community with them (see Section 3.5.3). It is my hope that this method will help designers move beyond ‘’empathy” to understanding disability culture and becoming allies and accomplices.

Alice Wong is one cultural creator who spearheads the disability visibility project (DVP): a platform for *‘’creating, sharing, and amplifying disability media* *and culture."* DVP specifices that it *''believes that disabled narratives matter and that they belong to us."* [348] This highlights an important aspect of DREEM: the ownership and agency of disabled makers. DREEM is all about enculturation by seeking out disabled stories and internalizing them. These stories are required to be by disabled creators, not about them. When many unenculturated designers (like myself) first engage with design for disability, they are coming from a place of technosolutionism. Instead, DREEM requires them to engage with disabled people as creators themselves with the agency and ownership that comes with that view.

I don't recall if it was an accident or an intention, but DREEM's acronym speaks to the dreaming disabled activists do (see Section 3.6). As discussed briefly in both Chapter 2 and Chapter 3, dreaming is an act of resistance done by disabled people; bringing better futures into being. It also speaks to the ways we can design the future. As Leah Lakshmi Piepzna-Samarasinha describes in ''Care Work: Dreaming Disability Justice":

> ''For years awaiting this apocalypse, I have worried that as sick and disabled people, we will be the ones abandoned when our cities flood. But I am dreaming the biggest disabled dream of my lifedreaming not just of a revolutionary movement in which we are not abandoned but of a movement in which we lead the way. With all of our crazy, adaptive-deviced, loving kinship and commitment to each other, we will leave no one behind as we roll, limp, stim, sign, and move in a million ways towards cocreating the decolonial living future. I am dreaming like my life depends on it. Because it does." -Leah Lakshmi

> Piepzna-Samarasinha, ‘’Care Work: Dreaming Disability Justice” [85]

In her latest book, Wong connects personal storytelling to dreaming:

> ‘’Memoirs are valuable because remembering allows us to access our imagination and power the power of memory is linked with the ability to manifest ones future,” -Alice Wong, ‘’Year of the Tiger: an Activist’s Life” [349]

Dreaming, creating futures, that’s design!

4.1 A Personal History of the Project

Dreem came as an idea from a first-year class introducing methods used by various professors within our department. The inkling of thought began when Noah Wardrip-Fruin introduced close reading of the method used for looking at software and its history within visual arts. I had done close readings of literature in high school, but it was exciting to learn that can be applied to anything. I was excited about the way software variable naming conventions alone can surface the politics of the coders. It wasnt until my second year (2019) that I began thinking about ways to leverage close readings with content made by disabled creators. Media made by disabled creators has helped me so much; at that time I was using it not only to learn about technology design and accessibility, but about myself and my family, learning about concepts of ableism I had experienced, but had no words for yet. I didn’t quite know what it would be good for, but I was interested in applying close readings as a methodological experiment.

This dissertation is presented out of order. DREEM was the first study in this research agenda. In a journal dated 4/7/24, I write:

> *Interesting that I did DREEM first I think things can be felt without knowing the background / how to put a name to it fully. Maybe a part of the reason DREEM has been rejected is because I was still figuring out the full picture. It went from an interesting methodological experiment to addressing all kinds of harms in the field - I just didn't know how to talk about those harms yet.*

The motivations behind creating the method were not originally clear at the time, because I hadn't experienced academic research fully enough to know why a method like this didn't already exist (See Section 3.5.2 for a discussion of what knowledge is valued as research).

In a way, I was seeking out a method I wish I had had when I started. When I came to accessibility work, I had had experiences of disability and ableism both for myself and secondhand doing care work with family members. But - I didn't have words for it, and I wouldn't have known what to think of disability as culture. Over the years, the cultural labor of disabled creators was a guiding light for me. While a lot of the academic content and popular culture made about disability was often sticky feeling, I sought out being in community with disabled people and engaging with what they made.

One of the best parts of developing DREEM for me was having an opportunity to work with so many different people who were learning aspects of disability culture. In a journal entry dated 8/10/23 I highlight some of those experiences:

> *Today I met with the research group who has been using DREEM. They have been coming at it from ...[an interventionist] angle. I suggested maybe they might start with DREEM to help me test it out and get started on their project ... They've been collecting media of people's executive functioning strategies. Today they came to me with CONCERNS. They wanted to restart the project. They had attended two talks by people with ADHD that were coincidental (not related to their media gathering) and they felt that their approach was technosolutionist. They now want to take a critical disability lens to the whole thing. I said no stop! You just saw media (presentations) created by your target population and it made you change your mind and see things from a new angle. That's the point of DREEM! You don't need to restart, this is part of the journey - keep documenting it! I'm so excited that they are thinking about it. It seems like its working... they said they are used to system building so it's interesting to be taking so much time to consider the thing they will or won't build.*

This highlights the benefit we have by being in community with each other and figuring it out together. The resulting article and method follow:

4.2 Abstract

Empathy-building, the first stage in human-centered design, often involves methods that inadvertently reinforce negative stereotypes and biases toward disabled communities. In this work, we introduce a new method: Disability-Related Empathy from Existing Media (DREEM). This method focuses on enculturation rather than traditional ideas of empathy. DREEM leverages media created by disabled individuals to facilitate a deeper, culturally informed understanding. Cultural content is rich with authentic perspectives and tacit design knowledge from people with disabilities. Our four-step process includes (1) discovering relevant media, (2) close reading, (3) reflective journaling, and (4) aggregation of insights. In this article, we present our process of creating DREEM using research through design in multiple research and education contexts. Our findings show that DREEM can be applied in both design classrooms and research contexts to foster a more nuanced understanding of disability for newcomers to the space.

4.3 Introduction

One of the essential parts of working in the field of HCI is the 'discovery stage' or the phase of empathy building - the process of "knowing the user" [350–352]. In this stage, practitioners uncover research questions and design problems. To do so, they "set aside their own assumptions" to understand a user's emotions, needs, wants, and objectives [350, 352]. This often proves challenging for practitioners who have vastly different lived experiences than the subjects of their research. For example, many approaches toward building empathy ask researchers to imagine the experience of living with a disability (i.e., empathy maps, disability simulations). This involves exercises such as simulation, which has been shown to cultivate negative perspectives and pity towards those with disabilities [316]: outcomes that are contrary to the goal of establishing empathy. Yet, when it comes to disability, this and other suboptimal (even counterproductive) empathy-building methods remain standard practice in our field and teaching practices.

In this paper, we report an emerging alternative method for empathy building. While we developed this approach for disability-related empathy, it could be extended to other groups of users as well. DREEM (Disability Related Empathy from Existing Media) centers content made by disabled creators [*]. The perception of disabled people as needing the help of designers rather than being problem-solvers themselves pervades design pedagogy and our field as a whole [49, 63, 83, 126, 264, 297, 353]. Instead, DREEM asks researchers to deeply engage with the cultural labor [85, 328, 354, 355] of disabled creators as a first step toward working with a community. We believe centering disabled creatorship from the beginning places epistemic power in the community: positioning disabled people as knowers, makers, and storytellers [264] instead of needing help [46]. Seeing disabled people through a deficit view risks encouraging saviorism and technosolutionism in research projects [7, 39, 41].

In this article, we explore how immersing oneself in the content created by disabled individuals can be used to build empathy. DREEM is a way to begin understanding communities before engaging directly with community members during later stages. Taking on this investigation of the community before (but not as a substitute for) working directly with users builds a basis for appropriate future interactions. We believe designers can and should build authentic understandings of the experiences of populations with disabilities as a precursor to participatory or community-based work. Seeking understanding ahead of time could be a small

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[*] Person-first disability language (e.g., person with disabilities) and identity-first language (e.g., disabled person) are used interchangeably throughout this paper

step toward alleviating "the potential over-reliance and under-acknowledged use of people with disabilities for their 'access labor'..." [37, 98] (See Section 4.4.2). Indeed, standard research processes like iterative design ask a lot of participants, *especially* those who are already marginalized by our social systems [52]. We encourage researchers to both take on this labor, and critically reflect on the spaces they design in by utilizing the stages of DREEM.

This paper examines how close readings of media produced by people with disabilities can lead to productive empathy building and the discovery of authentic, meaningful research agendas. DREEM is built off of prior development and critique in this space of empathy building with disabled populations [350, 352, 353, 356]. It works against tropes of ableism that come from traditional approaches to the empathy-building process. Our primary contribution is a novel 4-step method for building empathy with disabled people via media created by people with disabilities. We have included materials for using the method, as well as resources for educators who might wish to incorporate the method into design curriculum. We have included training material, data logging templates, and a tool for analysis.

4.4 Background and Related Work

4.4.1 Conceptualizing Disability

Over a decade ago, ASSETS scholars called for the use of a critical disability lens while designing and developing assistive technology for disabled individuals [46]. Until this point (and beyond), the standard framing of assistive technology was rooted in medical discourse rather than critical disability discourse. The medical model establishes disability as an inherent problem in the body to be “fixed” or “normalized” by intervention. As opposed to medical care (people need and deserve medical attention), the medical *model* upholds narrow ability norms to the point of disappearing disability. More socially-oriented framings emphasize the sociopolitical context and environment as *creating* disability by denying access to particular bodyminds [55, 77, 357, 358]. These framings tie the concept of disability to specific human-made constructs such as architecture (i.e., who do stairs and heavy doors exclude by default?) and political systems (i.e., what would disability be without a capitalist notion of productivity?). In addition to these framings, disability can be a cultural identity [55, 348, 359–361]. As dominant medical discourse has historically influenced the design of assistive technologies, designers must intentionally extend beyond it. This paper emphasizes frames of thinking that legitimize and celebrate disabled ways of knowing. DREEMing can potentially offer a window into the sociocultural fabric of disabled communities.

4.4.2 Motivations

A recent survey of ASSETS and CHI accessibility work showed that only 16 methodological contributions (3.2% of all) have been made to the accessibility community since 1994 [37]. These methodological contributions include findings on how traditional HCI methods differ in use with disabled participants [362, 363]. In this section, we discuss the motivations and values behind developing a method from scratch. We were guided by the question: **what does it mean to create a method that values disabled contributions?**

Accessibility research too often remains separated from the authentic needs of disabled communities [47, 126, 297, 364]. Actionable processes toward addressing these issues have been called for [364]. We are developing DREEM to give researchers actionable steps to address contemporary critiques of accessibility research. DREEM is intended to support new scholars and those interested in contributing to the SIGACCESS field.

Responding to Critiques of Empathy

Methods for empathy building for populations with disabilities primarily include those described by Wright and McCarthy as ‘’empathy through the imagined other.” The most commonly used tool for disability-related empathy* is the disability simulation [316, 368–373], in which a designer will attempt to try out having a disability for a short length of time (by wearing a blindfold, going out in a wheelchair, etc.) Proponents of these methodologies encourage designers to spend a day in another’s shoes to discover pain points in their daily lives and how others interact socially with them. Interestingly, in their cornerstone paper on empathy in HCI, Wright and McCarthy *only* describe disability and illness as the use case for empathy through the imagined other.

It has been previously pointed out that this approach to ‘’trying on” disability doesn’t work as well as it is intended [316, 356, 369]. Designers can only draw on their perceptions of the disabled experience and are likely to reproduce societal harms. Watching a classful of students try on disability with these results

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*This is also the only disability-specific method for empathy building. All other methods are common ethnographic techniques [352, 356]. Though other common methods (i.e. empathy maps[365] based or personas[366]) share the issues discussed in this section [365, 367] can be harmful to the 25% of disabled people who are also in that classroom. One empirical study showed that these design exercises actually worsen stereotyping, discomfort, and pity towards people with disabilities [316] The author, Nario-Redmond, notes that feelings like the freedom brought by mobility aids are not captured, only negative feelings of restriction. Nario-Redmond recommends engaging with real disabled people. Likewise, in ‘’Why I won’t try on disability and neither should you” Abreu notes that disability simulations didn’t tell her as much as time spent with disabled friends and family [369]. These practices also don’t seem to acknowledge that there are likely disabled students in the room. Disability simulations continue to be standard in design education.

As a whole, empathy as a design tool has been criticized for eliminating the empathized, putting the designer at the center of knowledge. Bennett and Rosner provide an in-depth critique of disability-related empathy in HCI [356]. They illustrate that not only are designers’ conceptions of disability prioritized over real experiences in empathetic activities, but empathy is also used to take credit for disabled contributions to projects. Bennett and Rosner encourage researchers not to explore ’being like’ but ’being with’ disabled people [356]. We extend this position by giving designers and researchers a tool to learn how to be in community *with.*

DREEM encourages designers to conceptualize the empathy-building stage of human-centered design as one of enculturation rather than empathy. Enculturation is the gradual understanding and adaptation toward a new culture. It *“concerns the acquisition of those rules, understandings, and orientations that provide, among other things, contoured maps of the landscape of community life* *and heuristic guides for effective participation"* [374]. Enculturation effectively describes DREEM as it is a tool for preparing researchers and designers to engage in communities, and a tool concerned with a particular culture. As discussed in section 4.4.1, disabled populations can be viewed as individuals with deficits or cultural communities with values and practices as complex as any other cultural group. As a designer, it is tempting to take the deficit lens: framing individuals as problems to be solved fits the narrative of designing solutions (reinforced by ableism as the societal norm). DREEMers don't need direct access to disabled communities to find them online. As a method of enculturation, DREEM positions disabled people with agency: as creators themselves, not to be fixed but conspired and collaborated with.

Honoring Existing Cultural Labor

People with disabilities face extra labor and time costs in everyday life (see ''crip tax" [375]). Although there are a multitude of ways that crip tax shows up, we have highlighted two areas of labor that we see as important considerations for the research and design process when engaging with disabled individuals and communities. We encourage researchers to work towards giving time back to disabled individuals and have structured DREEM with that value. We look hopefully toward a future where technology, policy, and society help everyone put their time into the things they want rather than simply survive in our existing systems.

Cultural labor

Cultural labor is the organizing and creative work done to contribute to a particular culture, like disability culture [66, 85]. Cultural labor can be in many forms of advocacy including books (e.g., Nothing About Us Without Us [66]), media (e.g. cripple media [359]), or shared accounts (e.g., Resistance and Hope [302]). Existing cultural labor is what DREEM relies on.

Access labor refers to the work that people with disabilities are required to do in order to have their access needs met [37,85,98]. Access labor includes 'informant fatigue' (e.g., being asked too often to share repeated personal details [91]) and 'forced intimacy' (e.g., being required to divulge deeply private information in order to gain access [50]). This can also mean maintaining friendly relationships with caregivers [99], requesting accommodation (often needing to prove disability) [79], or the everyday work of living with a disability in an ableist world [100]. We posit that DREEMing ahead of participatory sessions can alleviate access labor for participants, and allow researchers to ask more meaningful questions rather than falling into the common trap of informant fatigue and forced intimacy.

Research engagement can be a form of access labor. Participants may use their time/labor to engage in research projects for access purposes. The research process can mirror broader social systems that already fail people with disabilities and multiply the harm [52]. For example, the exchange of private information for access is a common trade-off for people with disabilities [50, 376]. One perk of participation is often gaining access to otherwise expensive or unattainable data [377]. Another reason for choosing to put labor toward research studies is to have a needed technology that is still in development, participating in bringing it closer to fruition. Unfortunately, design research often does not make it to the market [82].

Fighting Design Saviorism, Technosolutionism, and Internalized Ableism

The empathy-building stage helps designers find projects and research agendas that are more deeply meaningful to the communities or individuals at hand. It is important for technologists and designers to confront issues of ableism, sexism, racism, homophobia, etc. because we build and maintain worlds. As discussed in Section 4.4.1, technology development follows dominant ways of thinking. This is not by accident, technology is developed by humans who carry their own biases and beliefs at that particular time and place [378]. Because the artifacts we develop have politics [378], they often carry broader societal implications.

One underlying motivator that effects design is **internalized ableism.** Internalized ableism exists within everyone as a baseline and may be difficult to uncover. Internalized ableism is an individuals default belief that able-bodiedness is the better, more pristine state of being when really it is morally neutral. For disabled people internalized ableism often comes out as a feeling of shame. More broadly *"Ableism is a system of oppression that favors able-bodiedness at any cost, frequently at the cost of people with disabilities"* - Stacey Park Milbern [36]. It is important to interrogate ones own internalized ableism when working in this space so that our designs dont reinforce this norm. Without consistently and consciously confronting our internalized ableism we risk it leaking into our work practices and the technology we design. Confronting ableism is a core necessity for DREEM, and learning how to see it is a necessary first step. In media, Ableism might show up as inspiration porn [379], infantilization [380], solutionism (ie. "have you tried yoga?") [381, 382], and more [383].

Because ableism is ingrained in society, it informs what we see as problems to solve. The issues that receive our attention may not be problems, or "solvable" at all. Many sociopolitical issues cant be addressed with technology alone, yet we often attempt to apply technology as a save-all. **Technosolutionism** happens when designers become excited about a technological advancement and then gallantly use it to fix problems they *believe* people with disabilities face [7, 41, 66]. Although it contradicts HCI's standard of working with users to solve their issues, it is still a frequent practice for marginalized participant communities. Irani et al. aptly describe a venture that takes this approach as *"a solution in search of users"* [39]. In her 2019 ASSETS keynote, Karen Nakumura highlighted smart white canes as one such example of something that already works well, yet HCI designers keep wanting to "fix" the technology despite no one asking for it [67].

By solving problems that may not actually exist, technosolutionism often leads to fruitless technologies. Technosolutionism may partially explain the high abandonment rate of assistive technologies [384]. Liz Jackson refers to useless fixes as a *"Disability Dongle: A well-intended, elegant, yet useless solution to a problem we never knew we had"* [48]. **Design saviorism** is the view that as designers we can and should rescue or fix what we view as the problems of marginalized communities. It refers to an able-bodied person saving a disabled person from their challenges as charity [40]. Technosolutionism stems from the ableist trope of solutionism. Design saviorism stems from the ableist trope of tragedy and needing to be saved by someone more capable. Saviorism is tied to ideas of colonialism [39]. It is analogous to white saviorism [385] and voluntourism [386] in the way that the "savior" benefits from the narrative while potentially negatively impacting those they are trying to help.

We believe that understanding a user's true lived experience while interrogating our perspectives helps avoid technosolutionism and design saviorism. We believe DREEM is an effective way to start design with an understanding of lived experiences (through close readings of media) and uncovering our own biases and relationships with the topics at hand (reflexivity).

4.4.3 Influential Methods and Approaches

As mentioned in Section 4.4.2, there are relatively few methodologies designed specifically for use by the SIGACCESS community. Instead, the accessibility research community draws on existing research methods from many domains. In this section, we discuss the multidisciplinary methodologies that informed the creation of DREEM.

DREEM utilizes media made by disabled creators to help designers engage with authentic stories: focusing on the designer's engagement with the media rather than using it as a data source for traditional analysis. SIGACCESS authors have previously used social media as a rich site for more traditional data analysis [88, 105, 387–389]. We hope to support and extend possibilities for this existing practice.

Close Readings

Close readings are the careful, deliberate observation and re-observation of an artifact with the goal of more deeply understanding it [390]. The method originated in literary studies and is typically conducted on text. Close readings can also be applied to designed artifacts such as games [391], software [392, 393], music [394], music videos and performances [395], film [396], images [397], and more. Scholars in the humanities most typically utilize close readings, but we believe technologists and designers can meaningfully leverage them.

In close reading, an observer will note what is and what is not there (i.e. *''What is in the background?"*, *''Why did they make this editing choice and not another?"*) They will situate the artifact within a broader context (i.e. *''Who is the intended audience?"*, *''Why was this artifact made?"*). This attention to detail and context has the potential to help us understand the experience of living with a disability more deeply. Unsolicited by researchers, creators naturally present meaningful topics, reflections of their everyday experiences and themselves. Looking more closely, one might uncover the creator's worldview, intentions, constraints, and values. In short, close readings can help us understand creators and build empathy.

Netnography

Netnography is an online research method originating in ethnography and is often employed by social scientists and anthropologists [398]. Netnography is a subset of digital ethnography with netnography focusing more on the individual encounters across social media. Netnography maintains many of the characteristics of traditional ethnography, without focusing on typical embodied phenomena (i.e. body language). Instead, netnography is primarily concerned with the context of online media such as text and multimedia [399].

Netnography uses spontaneous data and conducts observation without intruding on online users. It is regarded as more naturalistic than other approaches such as interviews, focus groups, surveys and experiments [400]. These online community members often share in-depth insights about themselves, their lifestyles, and the reasons behind the choices they make [398]. DREEM adopts concepts of netnography to uncover the experiences of disabled creators online. While DREEM could feasibly be extended to include relations within social networks, we do not adopt that focus of ethnography.

Participatory Design and Codesign

These related design approaches strongly emphasize a need for user involvement in all stages of design. When addressing the next generation of issues that matter, all stakeholders should participate in the design of technology they will use [131]. From exergames for wheelchair users [401] to speech therapy [402], virtual reality for teaching people with developmental disabilities to identify emotions in others [403], and robots for physical rehabilitation [404], technology can effectively be designed with people with disabilities to serve their needs. It is clear that participatory design has been commonly adopted in the SIGACCESS community. Codesign sometimes brings members onto the research team in full. Similar to these ideas, Goodley describes knowledge production in disability studies as a continuum containing non-participatory research (researcher-led), participatory research (researcher invites participants into research), and emancipatory (co-researchers) [405]. Because interacting with community members via participatory design, codesign, and more is a standard within our domain, researchers must understand how to be in community with disabled populations. DREEM fits within the larger umbrella of participatory methods by leveraging existing cultural work to educate researchers prior to co-design sessions so that they can be more effective and appropriate. DREEM is a precursor to participatory work.

Reflexivity and Autoethnography

Reflexivity and autoethnography are two qualitative research strategies that produce knowledge via the interrogation of personal experience. We have found practices relating to these strategies to be an essential part of DREEMing because they have the potential to reveal the writer's evolving understanding and internalized assumptions and biases relating to the data. We see this as necessary for understanding any community more deeply, but especially for those who have been historically marginalized. See Section 4.4.1 for a deeper discussion of the necessity of deconstructing internalized ableism.

Reflexivity is the practice of "awareness of ones own subject position and relationship with a research project" [406]. Positionality is one form of reflexivity but relates to the whole context of all stakeholders in a research project rather than just one person's understanding of their relation to the project [406]. Reflexivity has been taken up by and called for by many within the domain of human-computer interaction [407–409] including feminist HCI scholars [249] and scholars working toward social justice [12, 251].

Reflective journaling is a reflexive tool conducted by intentionally relating one's own experiences and contexts to the material one is investigating. This strategy "actively engages the student with the content in an intensely personal way" [410]. Reflective journaling helps learners to construct their own knowledge rather than passively absorbing it [411]. This work in critical self-reflection is already highly present in the HCI design community [407, 409, 412] and has been noted as especially important for crip-affirming futures [82]. They function as a space to congeal ideas that are forming while in this exploratory stage.

Autoethnography is a type of ethnographic work that is conducted on one's own experiences and contexts. "Autoethnography is a theoretical, methodological, and (primarily) textual approach that seeks to experience, reflect on, and represent through evocation the relationship among self and culture, individual and collective experience, and identity politics and appeals for social justice" [413]. The results of autoethnography then "represent [the autoethnographer's] thoughts, emotions, collective experiences, and social processes associated with an identity or issue and then contextualize them in broader, societallevel phenomena" [414]. This approach may employ a standard written essay format, a diary log, or handwritten annotations as well as more artful forms such as plays, art, music, and poetry. Some examples of autoethnography conducted in access contexts can be seen in [40, 309, 415, 416]

Memoing is a tool that many ethnographic and autoethnographic researchers employ. Memoing is a flexible strategy that qualitative researchers at any level of experience may choose to apply. Like reflective journaling, the process generally includes note-taking and journaling to connect ideas. Memos can take any form the researcher deems fit: journaling, scrapbooking with data, audio recordings, etc. Memos are also similar to field notes but do not only relate to field observations. Instead, they can be a space for researchers to amalgamate a breadth of different ideas whether they are related to personal experience or observation. This notation process can help researchers to make connections and situate data within a broader context [417].

Beyond revealing internal processing and bias, and serving as a space for connecting ideas, these practices are representations of generative intermediate-level knowledge [418]. Intermediate knowledge is an outcome of design research which is neither a generalizable theory nor a design instance (i.e. annotated portfolios, guidelines, etc.). In our case, recognition and articulation of patterns and social circumstances could inform later research practice.

The concept of self as a tool for data to filter through and the techniques discussed herein are core to qualitative research more broadly [417]. Overall we see these strategies as well situated for developing new understandings of communities while connecting them to personal experience (two steps necessary for empathy building).

4.5 Methods

We took a research through design approach [419, 420] and employed DREEM while iterating on its implementation. These iterations, reported in Section 4.6, have helped form the method additively over the span of 5 years. We have successfully adapted DREEM to both research and classroom settings across multiple universities and course levels, from high schoolers to master's students. A final version of the method can be seen in section 4.7.

To develop the DREEM framework we began with these 3 steps:

1. Discover Existing Media

2. Close Reading

3. Reflective Journaling

The initial three case studies were the most formative, and are reported most thoroughly in Section 4.6.1. The particular methodological context of each application is stated in its corresponding section along with how it has shaped the resulting method (Section 4.7). Throughout these applications, various resources for applying DREEM in education have been developed and can be found in footnotes for those who wish to implement the practice in classrooms or research settings.

For each application, we had researchers and students partake in at least the 3 steps listed above either before beginning a research/design project or as a part of an introduction to community-oriented research more broadly. In each case they iterated on these steps individually or in groups. DREEMers were free to explore any media form of interest, platforms, and communities as long as a disabled person created the content. We collected anonymous pre- and post-survey data using various adapted measures for some iterations. These surveys included qualitative questions about the method and an adapted version of the Teach Access Survey. The Teach Access survey was developed by the Ability Project [421]. Questions on Web Content Accessibility Guidelines were removed due to lack of relevance. It was chosen because of the intended audience and topic coverage (technology-oriented students) The survey consists of 11 items (reduced to 10) rated on a 5-point Likert scale. The first 8 items (reduced to 7) are self-reports of confidence in understanding of accessibility concepts. The last 3 are self-reports on interest in pursuing accessibility-related work.

4.5.1 Positionality

All authors have been asked to engage in and/or teach disability simulations in higher education. The authors have found themselves having recurring conversations about the challenges of onboarding new students into the space of accessibility research. We work in engineering departments at two academic research institutions in the US. The authors are early faculty and late-stage doctoral students. Onboarding and mentoring new researchers is vital to our careers as we create our labs and direct research projects. Our team comprises researchers with and without disabilities. Being disabled accessibility researchers impacts how the research community sees us and how we see *research about us.*

4.6 Iterations on DREEM

In the following sections, we report applying this emerging method to various contexts in order to develop it. Table 4.1 contains details of each iteration.

4.6.1 Building DREEM with Undergraduate Researchers

In this section, we describe the outcomes of employing DREEM with four undergraduate research assistants (RAs). Prior to recruiting undergraduate RAs, the senior research team, who designed the initial version of DREEM, completed steps 2 and 3 on and episode of *Planes Trains and Canes* [*] independently before collaborating on adjusting our initial DREEM data collection process. We in-

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[*] (A youtube series by Professor Mona Minkara in which she documents her global travels [422] `https://www.youtube.com/watch?v=B1sWtT-wShI`)

Sec.	Goal	Participants	Adjustments
4.6.1	Test and refine an initial iteration of the method	3 senior researchers & 4 new undergraduate researchers within varying programs	-
4.6.2	Apply DREEM as a design thinking tool: the first step toward design with a community	6 high school summer research interns over 8 weeks	(1) Applied in design thinking context (2) lo-fi prototype outcome (3) Harnessed social media algorithms to find new media.
4.6.3	Teach at scale using DREEM in coursework that utilizes the human-centered design approach	120 Undergraduates in an upper-division User Experience course, 32 Masters students in an accessible game design course	(1) Topic area rather than open exploration. (2) Introductory stage disconnected from design ideation. (3) Formatted as a canvas module serving as the empathy-building stage of the project-based courses.
4.6.4	Use DREEM as a method of enculturation to introduce new researchers to communities they will be working with but may not have nuanced understandings of.	20 new undergraduate researchers in Misfit over the span of 2 years	(1) Not connected to a specific project. (2) Last step for aggregation is creating and sharing a piece of media.

Table 4.1: The goal, participants, and adjustments made for each of the 4 Iterations on DREEM found in Section 4.6

cluded our experience as an example in the training materials we developed. We recruited four RAs through department newsletters and by advertising in classes we teach. [*]. We accepted all applications and hosted a 1-hour information and training session for the project.

The training described the motivations of the work, instructions on how to carry out the work, and expectations [**]. We asked undergraduates to reflect on their interests and confirm whether or not they wanted to participate as collaborators.

Over the course of 3 weeks, RAs used our close reading data collection DREEM form [†] to independently and asynchronously conduct steps 1-3. Researchers explored media freely. We had a recurring weekly check-in where we discussed progress, research directions, and reflections as a team. Our specific case studies were born from exploration, and interest-driven directions led by the RAs. After 3 weeks, RAs participated in inductive data analysis of their findings. After an inductive analysis of all collected data, the close readings and reflections were sorted into 8 emerging non-mutually exclusive themes: ableism, aesthetics of personal expression, autism, traveling with a vision impairment, everyday tasks with a vision impairment, tourettes, mobility, and communication, [‡]. We three, which were useful in evaluating our initial version of the DREEM method including: ableism, tourettes, and beauty products and aesthetics.

We present three exploratory case studies from this exploration that helped to

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[*] Our research flier is included in an editable form in our supplementary materials at https://tinyurl.com/DREEMRecruitment

[**] An editable version of our training slides are available in the supplementary materials at https://tinyurl.com/DREEMTraining

[†] available in the supplementary materials as an editable Google form at https://tinyurl.com/DREEMForm

[‡] which are all available in the supplementary materials at https://tinyurl.com/DREEMData

form the DREEM framework. We then present a survey of researcher learnings from conducting these case studies.

Key Takeaways: Attitudes towards disabled communities changed, and researchers were spontaneously exposed to key issues of systemic ableism and barriers to access. Inductive analysis was difficult for uninitiated researchers because it required training and practice. One of the case studies highlights that the method could benefit from focusing on one topic area from the beginning.

Case Study: Ableism

Three researchers close read five media sources resulting in the topic of "ableism." Sources included two text-based articles, one TikTok video, and two YouTube videos. Each of these media addressed and described different aspects of ableism encountered by the creators. The content ranged from educational to emotional and personal.

The first article described the author's experiences during a year of lockdown due to the COVID-19 pandemic. The second article described the experiences of disability in a hospital setting. Both addressed the source and impacts of ableism on their respective experiences. For the second article, the researcher was unable to finish the close read as it was "really emotional," relating to their own experiences. They chose to put it away incomplete for the time being, but their partial close read and reflections still served as useful findings. We discuss possible difficulty in doing this type of analysis in Section 4.7.2.

The YouTube videos were longer-form content that was more educational and explanatory in nature. One was about traveling in Paris with disability and the other was a video log (vlog) educating about ableism. The third video was shorter: at the time of viewing TikToks were constrained to one minute long. This was a personal description of how a student had experienced discrimination for both their gender and disability from their math professor.

Three reflective journals from different researchers were relevant to this set of media. Each was about the researcher's new understanding of disability and ableism after having close read the media. For example, one researcher wrote, ' '*[a]bleism and other discrimination could stem from the lack of education."* Another researcher wrote, ' '*systemic Ableism does not disappear even when top officials try to implement a fair approach."*

The close reading of content about ableism allowed the researchers to analyze and reflect on discrimination against disabled people from embodied, firsthand sources (sometimes even capturing ableist instances as they happen). For example, in the video about the student experiencing discrimination from their professor, the researcher reflected on the situation and asked some rhetorical questions in their close reading. For this researcher, they reflected on the use of particular language by the creator,

> "The professor responses and belittles the creator whenever they make a mistake or a question. The creator also relates this situation to being treated like a child. Do they make this comparison because they feel like they are smaller or helpless? There are other ways to describe being condescended or put down, and them deciding to compare to how a child is treated by an adult is interesting."

While the discourse around those with disabilities being treated like children is common in disability communities (i.e., infantilization [55]), close reading illuminated this to the researcher although they were not familiar. Later in the same video, the researcher comments in their close read,

> "It seems ironic that this school has an Office of Disabilities, and yet this professor still acts this way, which points to the fact that the office has not yet action for this professor's behavior. Has no student or other staff reported the professor? I wonder why."

In this one minute TikTok video, the researcher has come upon a number of different effects of systemic ableism. In the context of design, this researcher has engaged with some of the barriers that those with disabilities face. Understanding these issues as barriers to solve is crucial in the context of design for disability. Defaulting to positioning the disabled person as a design problem is an unintentional but frequent occurrence for designers who don't know the community.

Case Study: Tourette's Syndrome Case Study

We include this case study because it offers perspective on how the affordances of various social media platforms can affect the types of insights DREEMing can offer. 65 out of 70 of the close readings and reflective journals related to tourettes across 7 media sources were completed by 1 highly motivated undergraduate researcher. The media sources include a personal website (including a blog, Youtube videos, tweets, and a shop promoting Tourette's awareness), 5 YouTube Videos, and 3 TikToks. The personal website, called TicTastic!, is written by a 14-year-old musician who attends school, surfs, blogs, bakes, and has Tourette syndrome and Obsessive Compulsive Disorder [423]. Close reading a website that hosts a variety of media surrounding one individual's perspective offered a unique depth to this case study. In a reflection on the website, this researcher illuminated why it was important to engage with media made by disabled people:

> ''Seeing a new and darker side of her experience made me realize and remember that not all publicity/media coverages will correctly and fully represent a disability (or anything really)."

The question of intent in representation stuck with this researcher. They were particularly puzzled by some media on TikTok. While there were sources of *''wholesome"* media on TikTok related to Tourette syndrome (e.g., *''a couple playfully forgiving each other after a tic caused accidental physical contact"*), there were also videos that made them ponder the disabled creator's intent. For example, one creator created a highlight reel of their tics while cooking pasta and *''many of the comments seemed offensive- why did the creator post this? Was it for comedic relief, authentic lived experience, visibility, or something else altogether?"* We see the researcher's questioning of representation, motivation, and social reception as illuminating both various societal contexts of perceptions of disability, and humanizing the poster as someone with agency and desire for reception.

TikTok's short videos offer quick flashes of insight - whether they are rants, humorous moments, or viral challenges - but they often leave use with more questions than answers, which is not counterproductive. Youtube, on the other hand, affords much longer videos and more content. Watching longer form content allowed the researcher to capture minute interactions that may not be displayed in other formats. In a reflection about discovering content on YouTube, they were surprised at the patience of the content creator's friends and family:

> ''It was great to see the positive reactions in the moments of accidents, and that showed that these people understood how and why tics happen."

When using DREEM on various platforms, it is important to consider each platform's affordances as well as the intended audience the content was made for (e.g., a video for fellow members of a disabled community or a video for the general public).

Beauty Products and Aesthetics

We include this case study because it discusses a specific topic agnostic of disability. Two researchers considered three sources. Two of those sources were videos, the third was a makeup line release. The makeup line release was "Rare" by Selena Gomez. Selena Gomez has lupus and rheumatoid arthritis. The makeup line features products with spherical lids that allow a user to push down instead of squeezing to open.

The first video was a product review by Molly Burke, a YouTuber and makeup enthusiast who is blind. Through Burke's video we learned the importance of organization, scent, and embossing for her in any makeup palette. One researcher reflects on the impact of packaging in accessible design for makeups:

> ''Watching this video taught me to focus more on the small but impactful details on makeup products that affect ones ability to utilize it effectively."

Burke calls out large makeup companies for not having inclusive design. Researchers discussed that more people with disabilities should be making design decisions in the beauty industry - just like Selena Gomez's new line.

The second video is on a morning routine for particularly anxious days made by Asia Jackson. Our main takeaway from this video was that jewelry and fashion can be used to ritualize self-care. The researcher reflects: *''Putting on your favorite jewelry before beginning a process you may otherwise struggle with can make it more approachable and fun. Fashion can be used in many empowering ways, even if no one but yourself can see it. It is important that fashion is accessible in general and for the purposes of self-empowerment."*

People with different disabilities will likely have different product needs - some of which conflict. They learned that *''scent would be a barrier to people with chemical sensitivities, but Burke benefits from Too-Faced's food scented products"*. We were encouraged that the researchers stumbled upon the topic of conflicting access needs just by exposure to the community.

Researcher Learning Survey

As we explored what could be learned from existing media with the undergraduate team, we discovered one of the primary contributions of the paper: Actively engaging with media made by people with disabilities can be an effective way for new researchers to learn about communities and common systemic barriers. Each of the four undergraduate researchers had never previously conducted accessibility-related research. We did not initially anticipate changing attitudes toward disability, and only instituted a post-survey after discovering that it did.

Table 4.2: Teach Access Survey initial results

Q	On a scale of 1 to 5, how confident are you that you could do each of the following at this time?	Result
1	Give an example of a type of disability	5
2	Define Accessibility as the term relates to technology and media	4.5
3	Give an example of inclusive or universal design	4
4	Give an example of how accessible technology is used by people with disabilities	4.5
5	Give an example of how assistive technology is used by people with disabilities	4.25
6	Give an example of a technological barrier somebody with a disability might face	4.25
7	Define the purpose of the Americans with Disabilities Act	2.75
8	Learning more about designing or developing technologies for and with people with disabilities	4.5
9	Pursuing a job or career in accessible technology	4.25
10	Pursuing research in the development of accessible technologies.	4.5

The average response to each question of the Teach Access scale is illustrated in Table 4.2. It is no surprise that the team is highly interested in pursuing accessibility-related work (Q 8-10) as they self-selected for this research project. These outcomes are promising but don't offer much without a pre-survey (implemented in future applications)

In addition to the measures above, we asked the team to report on if and how DREEM has changed their perspectives, whether it was a good use of time for the effort, what was most difficult about it, and what impact (if any) DREEMing had on their knowledge of disability best practices. Researchers report better understandings of potentially ableist actions:

> ''I understand better the importance of including into any conversation instead of trying to speak for [disabled people]."

The team found value in engaging intentionally with social media:

> ‘’Instead of just doomscrolling or just scrolling in general, it gives me a focused reason to open social media and experiment with its algorithms to find communities I wouldn’t normally find myself in. I feel that it’s a good way to resist the algorithms that naturally filter us into niches.”

And that there’s still work to be done for access:

> ‘’[DREEMing] taught me certain aspects of accessibility, especially in the beauty industry, are still not accessible to most people with disabilities.”

All researchers report writing *’"thoughtful comments”* being the most difficult part of the close reading process. As one researcher puts it *‘’I kept on double thinking myself about whether or not I was properly empathizing with the subject’s needs”*

As a whole, researchers seemed to find the method worthwhile:

> ‘’DREEM helped to broaden my perspective and taught me to look beyond what is portrayed.”

4.6.2 DREEM with High Schoolers in a Summer Research Program

Based on our experiences with the case studies and student survey above, we found that DREEM had potential as a design thinking pedagogy tool for involving new students with communities they were unfamiliar with.

The aforementioned post-survey with 4 undergraduate research assistants showed promise for using DREEM as an empathy-building educational tool. To explore this potential further in a design context, we worked with 6 high school students over an 8-week Summer Internship Program. Students spent 10 hours per week DREEMing and 20 hours per week on other lab projects or doing social activities. For the first 6 weeks, students scraped content on TikTok from disabled creators. Students created new TikTok accounts and trained the curation algorithm on the ”For You” page by following creators with disabilities and liking their content. Students logged daily reflection journals, logged content using the DREEM form, and inductively kept a log of themes to tag the data using a hashtag format. For the remaining 2 weeks, students applied design thinking to their learnings and created 21 low-fidelity paper prototypes for designs inspired by TikTok videos they watched. Students completed this exercise after being taught the importance of working directly with the target populations. Some interesting prototypes include an origami-style foldable ramp made of lightweight materials, a wearable device that provides navigation instructions using directional haptics, a device that provides alternate forms of communication at museums, an anti-sloshing smart cup that beeps when full, a legislation idea requiring cars to have specific lights dedicated to honking, and a swimming headband that alerts users before bumping into the side of the pool [*]. Students reflected on how DREEM affected their perceptions of disability. Some of these quotes are included below:

> “I felt like I had a better understanding of“ableism” and how people with disabilities often do not wish to be treated in a way that signifies

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[*] prototypes can be found at `https://tinyurl.com/HighSchoolerPrototypesDREEM`

> they need extensive help."

> "I got to see how best practices stem from a multitude of criteria. Seeing examples of best practices through researching assisting people with disabilities definitely helped enhance this."

When asked about whether DREEM was a good time investment:

> "Yes. I felt like I got to see the intersection between technology and disabilities. I also got the see how factors like the media and social norms affect such assistive tech. Devoting time to self-reflect also helped me to design prototypes that might be useful to people with disabilities."

When asked about the challenges of DREEMing:

> "At first, it was hard to analyze my own assumptions and biases of certain aspects of disabilities objectively. During self-reflection, I had to spend more time on that and challenge myself to view the daily lives of people with disabilities in different ways."

As mentors, we saw marked improvement in student knowledge and empathy towards populations of people with disabilities. Each student seemed to gravitate towards a particular community they were interested in learning more about and building partnerships with.

Key takeaways: Students had specific areas of interest (i.e. swimming) they were interested in media for. Outcomes included things like policy change, but generally resulted in hackathon-esque ideas for design pursuits. Dreem did not prove substantial enough for generating full research agendas, rather it appears to be a method suited as a first step of engagement as enculturation.

4.6.3 DREEM in Upper-Division Human-Centered Design Coursework

Seeing the potential in both groups above, we extended this methodology to apply to several human-centered design courses at the upper-division undergraduate and master's levels [*].

Generally, reflective journals and close readings served as homework for the class. Project groups collaborated to find various media, and some appreciated doing close readings of the same media sources independently and being able to share.

Due to the length of the empathy module in the courses, this application was a shorter time length than any other. It lasted only about 2 weeks. This left students with less time to engage in communities meaningfully. Still, students found the short engagement meaningful: *''It increases awareness of disability fast, especially as someone who has little contact with disabled people normally....It doesn't beat getting to know a person with a disability closely in terms of actual empathy in my opinion."*

It is clear that the method left students hungry to learn more about the communities. The above response came from a student who did not identify as disabled and rarely interacted with disabled people (less than every three months, the maximum for that question). Other students also indicated feeling like they wanted

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[*] Canvas modules can be found here: https://canvas.instructure.com/courses/8262226

to engage more deeply with disabled communities after DREEM:

> *''I think it is definitely good to do more research about people with disabilities, but I didn't really feel like I was helping anyone while doing it- seemed more like a way to change my own mind about different groups and uplift them doing different things, but not really help them in any way."*

Indeed, the purpose of DREEM is to learn before engaging. Nevertheless, it is promising that this student felt individual change without directly engaging.

Overall, instructors (authors on this paper) found that DREEM as an empathy module served to get students asking deeper questions about design within community contexts and whether they ended up working on explicitly disability-related projects at the start. Reflective aspects helped students gain understanding: *''I liked the reflection aspects of it- it helped me to really think about what I was researching"*, but reflective journals were the only culmination of data gathered. In future iterations, students might benefit from a share-back of some kind.

Key Takeaways: DREEM was adapted to fit a large classroom setting in a short time span and still had a meaningful impact. Without the prototype ideation step, the practice lacked a formal closing of the exploratory period.

4.6.4 DREEM as onboarding for research assistants

While building DREEM with new research assistants, we saw all that they gained by going through the process as their first foray into research (Section 4.6.1). Since then, we have continued to use DREEM as a part of bringing new undergraduate researchers into our lab. For the past two years [anonymized] lab has been utilizing DREEM as a first-step onboarding method for undergraduate researchers who enter the lab. DREEM is conducted over the span of 4 weeks along with a primer on standard research practices within our lab and in HCI more broadly. This primer covers many aspects of research (i.e., What is the scientific process? How is research funded?). In this context, DREEM is not specifically tied to any project, community, or outcome. DREEM then, serves as a complimentary practice for them to become sensitized and encultured with disabled communities they are not yet familiar with - who they may or may not be working with when they join projects within the lab. Results of the Teach Access Survey from 8 undergraduate students can be seen in Figure 4.1

Unlike the initial foray with undergraduate researchers, we have undergraduates form teams based on areas of interest. We encourage that these areas of interest are not related specifically to disability and are something they are already interested in or knowledgeable of. DREEM Teams have ranged from topics as wide as 'XR' and 'Dance' to as specific as 'Jerma985 and his Fans with Autism and/or ADHD' (Jerma985 is a livestreamer)*. Researchers appreciated this freedom to explore a particular area instead of their initial impulse to think of disability as a monolith:

> *''One thing I like about DREEMing is how there are multiple ways to tackle the same general topic. For example, instead of all of us just doing disability as a whole, we got to be able to focus on a topic that disability heavily impacted.... a specific topic, I like how we were placed in groups instead of working by ourselves. I believe that working*

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*Throughout this section, we discuss some of the Dance team's outcomes.

> *in teams is better than working by yourself since you can bounce off ideas off one another and able to reach a better conclusion."*

Participants in this context seem to really appreciate collaborative work. One student valued social discussions over individual reflections and close readings:

> *''I think perhaps examining the content and resources we found as a group and having discussions about them with our groups (similar to a Socratic seminar or fish bowl type discussion), would have been more interesting."*

We did not account for the role group discussions play in aiding reflection. New researchers were able to learn from each other and the senior researchers through our limited group discussions. For example, we conduct one close reading as a large group example, based on a team's topic area and gathered media [*].

> *''Being able to deep read into different sources with the class/ more experienced researchers was really a highlight of the class. I wish we did more deep-reading as a group. Finding the sources and trying to analyze them through a researcher's lens was also very interesting."*

The primary difference in this case of implementing DREEM is that students culminate the DREEMing process by creating some form of media in which they aggregate the information they have learned. We found that students were excited about the various media they were close reading, so ending with a media-creation project to share with the lab at large seemed like an appropriate fit.

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[*] One example of this close reading was captured and converted into an informational miro page showing how to input data into the form. That page can be found here,

These DREEM outcomes have ranged from presentations to videos to posters. Pages of one such illustrative piece are shown in Figure 4.2. Looking at the dance team's outcome, we see they learned mobility aids are *''an extension of a person's body"*. Still, they nearly fall into the common ableist trope of inspiration porn by highlighting that people use dance to turn *challenges into opportunities.* While defaults still come through, the method has proven useful in getting undergraduates to think in nuanced ways about disability, and we have kept it as a standard onboarding practice in the lab.

Key Takeaways: Group discussions were valued in this context. The method could benefit from being taught in conjunction with anti-ableism training and other research methods. It's easy to fall into the trap of inspiration porn etc. without guidance.

4.7 DREEM

In this section, we introduce the 4 resulting steps to DREEMing: (1) Discovering Relevant Media, (2) Close Reading, (3) Reflective Journaling, (4) Aggregation. While these steps are somewhat sequential (find media before close reading it) there is a cyclical aspect. DREEMers can continue (1) throughout the process and will likely cycle on (2) and (3) as needed. Each step is discussed in detail with tips and insights derived from employing the method in the prior applications. Additionally, we include suggestions for presenting findings from DREEM and on benefits of DREEMing as a team.

Alt: *Teach access survey questions showing pre and post aggregated scores. All questions show increase, but the questions about pursuing accessibility as a career which stay the same.*

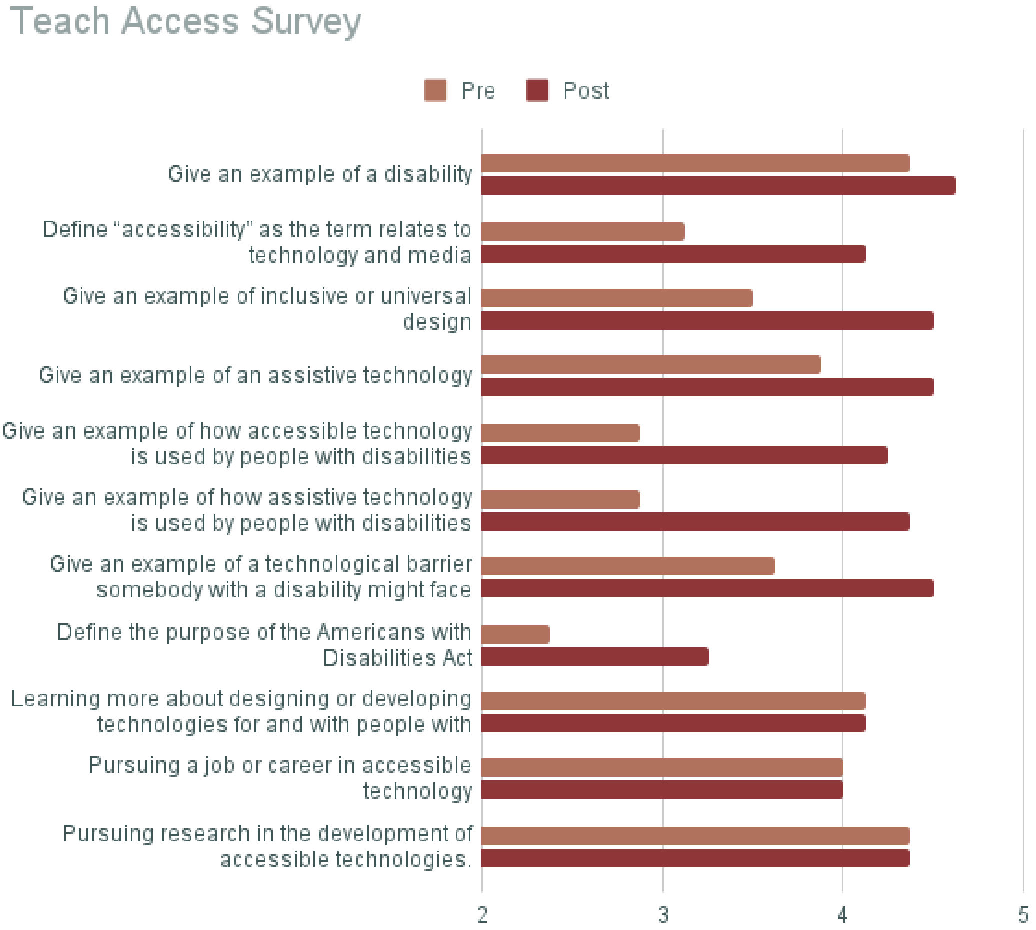

Figure 4.1: Teach access results with 8 new undergraduate researchers in Misfit Lab

Alt: *A sketch of a dancer with text illustrating findings: Mobility Aids: wheelchair dancing 1) specialized wheelchairs built for dance 2) seen as extensions of a person's body. Dance as expression: deaf dancers 1) loneliness from lack of connection 2) telling stories and feelings 3) gives a sense of purpose. Adapting: Tiktok 1) Challenges into opportunities 2) Incorporating disabilities into dance routines. Connection: Dance crews 1) creation of workshops for other disabled people (resources by disabled people and for disabled people) 2) sharing hope and possibilities*

FINDINGS

Mobility Aids

Wheelchair dancing
- -Specialized wheelchairs built for dance
- -Seen as extensions of a person's body

Dance as Expression

Deaf Dancers
- -Loneliness from lack of connection
- -Telling stories and feelings
- -Gives a sense of purpose

Adapting

TikTok
- -Challenges into opportunities
- -Incorporating disabilities into dance routines

Connection

Dancecrew
- -Creation of workshops for other disabled people (Resources by disabled people and for disabled people)
- -Sharing hope and possibilities

Figure 4.2: One page of the aggregation stage made by a team focused on dance. Showing both cultural understanding and potentially ableist pitfalls.

Alt: *Instructions for each stage appear numbered with a cycle indicated between 2 & 3. They read: 1) Discover: find existing media on topics of interest. The media must be made by a disabled creator. Look in the spaces you're already in - videos, books, games, and more. 2) Close Read: Take time to spend intentionally with the media you have found. Notice what is there and what isn't. Remember to always ask 'why?' Write down what you notice. 3) Journal: This is your space! Make connections between close readings. Take space to connect ideas to your life. What do you want to know more about? 4) Aggregate: Use any medium to collect information about what you found. What have you learned? What are your key takeaways? What will you do next?*

DREEM

DISCOVER

Find existing Media on topics of interest. The media must be made by a disabled creator. Look in the spaces you're already in - videos, books, games, and more.

CLOSE READ

Take time to spend intentionally with the media you have found. Notice what is there and what isn't. Remember to always ask *'why?'* Write down what you notice.

JOURNAL

This is your space! Make connections between close readings. Take space to connect ideas to your life. What do you want to know more about?

AGGREGATE

Use any medium to collect information about what you found. Look back at the information you've generated. What have you learned? What are your key takeaways? What will you do next?

Figure 4.3: Visualization of the 4 stages of Dreem

4.7.1 Step 1: Discovering Relevant Media

As a first step, find content! We recommend finding several sources to begin with and adding more as you go through the DREEMing process. Any public medium is a potential site for DREEMing including online content (blogs, images, videos, films, tweets, posts, etc.) or offline content (live performances, talks, zines, flyers, etc.). We have focused on media that can be found online for ease of access. It is possible to close read in-person performances, but having a recorded version offers the ability to sit with and return to the content. So far, participants have primarily chosen videos and text-based pieces. This method could reasonably be extended to any of the above (and more!).

Tips for Success

Finding media created by people with disabilities online can be a surprisingly difficult task. For example, when looking for content from creators with autism, searching for "autistic" might seem like a good place to start. Instead, YouTube's current top results are informational content made by clinicians, news outlets, and parents rather than perspectives from actual autistic people.

Finding relevant media may require some prior community knowledge (hashtags, vocabulary, etc.) that may be difficult to access for an outsider or someone yet to be enculturated. Finding doors and windows through hashtags, phrases, and snowballing was effective. Several examples and tips for success include:

- Search trend content with disability flavor: 'what's in my bag: chronic illness edition', 'amputee morning routine'

- Learn community hashtags and keywords : #ActuallyAutistic, #Spoonie, #CripTheVote, #ADHDTwitter
- Train the curation algorithm: Create a new social media account and follow only creators with hearing impairments as you find them.
- Snowball: Discover accounts that a creator you follow tags.
- Find collectives and anthologies: SinsInvalid, Disability Visibility Project

Important Considerations

There are several pitfalls to finding media on the web. We encourage DREEMers to carefully consider whether certain media sources need to be taken with a grain of salt, supplemented, or left out altogether. First, consider whether the media source perpetuates ableism and how. If you do not feel confident in detecting ableism or could use a primer, you might **first consider seeking out media made by disabled people on how ableism appears** (perhaps starting with Stella Young's ''I'm Not Your Inspiration"[424].

Second, media is not all-telling. It is made by humans who have their own agendas. Their views may not represent the community's. Disabled communities are multifaceted like any other. It is important to explore different perspectives. Third, anything that has been shared exclusively with a private network should probably be kept that way, be respectful of disabled people's privacy wishes. Fourth, different social media platforms have different affordances and cultures. Investigating multiple platforms will help increase the diversity of findings. Last, consider who the target audience is for the source (good practice for close reading).

It is likely that the media wasn't made to be informational and may present ideas in a way that could be difficult for an outsider (i.e. use terminology or make light of certain subjects that wouldn't be appropriate for an outsider to use). Generally, looking in topic areas or platforms you are already familiar with is the best way to find media.

4.7.2 Step 2: Close Reading

Next, read or observe the media and sit thoughtfully with it as described in Section 4.4.3. We recommend working systematically and using standardized collection measures [*]. Relevant details to log beyond the close reading itself include the source of the media, a short 1-5 word summary that makes skimming the data later easier, annotated screenshot(s), location in the media the close reading entry relates to (e.g., line number, time span in video), and keywords/tags. We enter each "complete thought" as one unit - these could be a few words or a few sentences. We also logged questions we asked ourselves that arose during the close readings. You can choose to immediately start logging your visceral reactions or start entering close readings after you've been fully exposed to the media, but we recommend doing both.

Tips for Success

Record your thoughts as they occur. These can directly relate to the content in the video or can be personal to your lived experiences. As you go, maintain a list

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[*] We include an editable Google form for DREEMing in the supplemental materials at `https://tinyurl.com/DREEMForm`

of keywords and tag each recorded thought. These keywords can make indexing easier later. Our team took advantage of Google Forms and spreadsheets for this step. In general, take your time through this step. It may be useful to step away from the media and come back. Multiple reads may lead you in different directions.

Important Considerations

People with disabilities are not always in control. Ask yourself who is involved in the media and what their roles and motivations are. It is possible that content will be emotional, provoking, or difficult to engage with like it was for the researcher in the Ableism case study. It is ok to set a piece aside, take it slow, and even change directions. Reflections may help.

4.7.3 Step 3: Reflection and Empathy Building

Reflection is a crucial part of DREEMing. The primary aim of DREEM is to learn about communities in an authentic and lasting manner. Reflection creates the time and space to absorb your learnings and connect them with one another. Reflection is an important part of making sustainable perspective change [425]. We recommend doing a session of reflective journaling after each analyzed media artifact. Maintaining a paper trail of your evolving thoughts also allows you to incorporate the learning process itself into the content analyzed via inductive thematic coding.

Tips for Success

We like using the following prompts for our reflections, but you do not need to follow a specific structure. You do not need to make each reflection similar in structure to one another and you can choose or combine prompts as they seem relevant.

- What trends or patterns do you see emerging?
- Have you learned anything new about the community you are studying?
- What could you improve about your logging process?
- What is valuable or not valuable to you as an individual about your process?
- If working with others, what are similarities and differences you are seeing in your logging or retrospective writings versus your peers?
- Have you learned anything that could inspire technology design?
- What questions will you explore next and why?

Participants sometimes answered all questions in one diary-style entry or elaborated on one of them. We keep these prompts at the top of our diary documents to inspire us.

4.7.4 Step 4: Aggregation of Learnings

After finishing with iterating on the first 3 steps, we found it was helpful to collect findings as a final artifact that can be shared with others. This step allows the researcher to reflect on their findings and talk through them with others. This step can be done in a group setting as desired by participants and can take any form (presentation, video, artwork, etc.). If a more formal, less open-ended aggregation is desired, you may consider writing up your findings as traditional close readings that focus on a particular topic and discuss multiple sources. [426] and [361] are examples of such close readings.

4.7.5 How to Present DREEM Findings

DREEM findings can be presented as their own findings or as steps within a larger body of work. In each case the presentation of the work will look slightly different. In the case that DREEM is presented as the primary finding, the outcome may simply be what was created in Step 4. In the case that DREEM informed a broader body of work, researchers can share important elements that are specific to the DREEM process such as: links to media analyzed, keywords and their frequency, and highlights of the individual close readings and/or reflections.

4.7.6 DREEMing as a Team

DREEMing can be done on your own or as a team. If you plan to work as a team, we offer some insights based on our experiences.

We found that DREEMing has the potential as an effective way for undergraduate research assistants and assistive technology newcomers to become acquainted with people with disabilities. DREEMing as a team offers the ability to discuss and build on each other's work. As has been discussed in other literature, teaching accessibility concepts to undergraduates continues to be a challenge [353]. We offer this as one framework for learning towards that goal.

It is not required for multiple team members to do close readings of the same media. However, doing so can offer insights from multiple perspectives. We found that comparing each other's notes led to fruitful conversations about the researcher's individual experiences and insights that might have been missed if everyone had been working independently. We recommend leaving time in your research process to read each other's close readings and journals and meet to discuss them. Teams should work together to find a logging process that works for everyone. Expectations for quality and length of passages should be set and continually talked about.

4.8 Challenges for Future Applications

DREEM has been developed specifically for design with various disabled populations, but the method could feasibly be used in the context of other communities. Future work is necessary to explore this possibility.

Two challenges with DREEM could be considered more deeply in future work. First, this method requires access to content created and posted online. Content creators with particular disabilities are relatively few on some mediums due to accessibility issues and societal barriers. Memes and GIFs, for instance, are often posted without alt text [427], so the participation of screen reader users with memes and GIFs may be lower.

Second, as discussed in 2.2.3, just because a creator is disabled does not mean they are free from internalized ableism. The challenge of training individuals to recognize and flag ableism and ableist tropes is ongoing. We have tried to mitigate this with our training and suggestions in this paper, but recognize this is a thorny issue that will need continual appraisal. One resource for further exploration is #CriticalAxis which is a site full of popular media (commercials etc.) with critiques and annotations [428].

4.9 Conclusion

In summary, we have proposed DREEM, a 4-step nascent method for using close readings of media posted by people with disabilities to become enculturated (rather than build empathy). Our primary contributions include materials for utilizing DREEM, including trainings, data logging templates, and a tool for visualizing close readings. We found that actively engaging with media made by people with disabilities is an opportunity for new researchers to learn about these communities and working with disabled people. The potential benefits of continuing this line of work include shared labor, authentic research problems, increased visibility of disability communities, and healthier partnerships with communities of people with disabilities.

DREEM surfaces and features existing work and labor of disabled people. The validity of research can be more rigorous if the source of inspiration is surfaced and credit is given where it is due. DREEM extends participatory design and community-based research from being inclusive on *how* something should be made to *what* should be made in the first place.

We were thrilled to see concepts of disability be introduced by exposure to content (infantilization, conflicting access needs). Broadly, we have seen newcomers to disability move from ‘’for” to ‘’with” by using DREEM [356]. We have seen them adopt views and understand nuanced perspectives, viewing disability as culture rather than a design problem. We are hopeful that this method will help create a generation of designers who are Allies and Accomplices [429] in changing systems for the better.

4.10 Acknowledgements

Thank you to disabled cultural creators and to the students who DREEMed with us.

Chapter 5

Discussion & Closing Thoughts

In Chapter 1 of this dissertation, I presented how HCI could change by taking on perspectives from disability justice practitioners. To illustrate the potential for change, I discussed the history of AT development and common perspectives on AT. Much of both position people with disabilities needing technologies applied to them rather than honoring them as designers, creators of new worlds [85], knowers, and makers [264] in their own right. To demonstrate the potential impact of situated disability knowledge, I showed several examples of concepts that could change AT design. This disability knowledge is not usually located in technology textbooks or even academic settings at all. As non-academic disability scholar Liz Jackson puts it:

> ‘’The best information about disability is not contained in books. It’s contained in the inquiry of folks who lack the capacity and resources to get a book published. But these tidbits don’t make a beautiful bookshelf display. Perhaps we should find a way to display them.” - Tweet by Liz Jackson, March 2022 [430]

Throughout this dissertation, I have illustrated approaches that center disabled knowledge as well as individual journeys of shifting mindsets toward disability justice (including my own). As seen in Chapter 3, DJ goes beyond honoring disabled knowledge and into critiques of productivity as value, emphasizing wholeness, intersectionality, leadership of the most impacted, and more. Each of these principles have potential implications for the practices of technologists.

To understand and contribute to the landscape of justice and technology, I conducted three studies with varying methodologies, including a systematic literature review of academic articles, semi-structured interviews with those interested in disability justice, and iterative research through the design. Throughout these studies, I kept the following research questions in mind:

★ RQ1: What are common practices for technologists who do justice and equity-based work?

★ RQ2: How do we teach these practices to HCI practitioners new to the space of disability and access?

To close, I present a summary of the findings in each study, significance of this contribution, practices found and emerging in this work, connections between Chapters 2-4, and a reflection.

5.1 Summary of Findings

In Chapter 1, I illustrate the research space, including terms used herein, an introductory problematization of commonly held beliefs about assistive technology concepts, a brief history of access research, and an intial view of what access researchers might gain by looking toward disability justice practitioners for guidance.

In Chapter 2, I showcase how the field of Human Computer Interaction approaches social justice as a whole. In this study, we present considerations for social justice research. In addition, we find that researchers have a tendency to respond to harm, but few engage with why it is occurring or what benefits to others may be reinforcing the harm's existence. While conducting this review, we found areas of social justice work in HCI that appeared underdeveloped. We draw attention to critical gaps in the field that require further attention to move forward, including inquiry into benefits, exploring under-researched harms, engaging with multiple axes of identity, and working at individual levels of interventions. Importantly, we call for systematic reforms for recognizing justice work which is usually slow and messy. We call on researchers to expand from deficit views and responding to harm into work focused on flourishing and joy.

In Chapter 3, I present interviews on disability justice. These interviews surface individual level practices and personal journeys not surfaced by academic reporting. I report on these journeys and practices as well as tensions of disability justice and technology research (coopting a community movement, epistemic issues, burnout, and access championship, and constraints of funding and research timelines). In addition, I outline teaching practices for onboarding others and participants' dreams for the future.

In Chapter 4, I report on the development of an empathy building method for enculturation into disability communities following findings from the prior chapters. DREEM asks researchers to engage meaningfully with disability cultural artifacts and requires 4 iterative steps: finding media, performing close readings, reflexive journaling, and aggregating learnings. DREEM was created in research through a design process over the span of 5 years. I report on findings from applications with a variety of learners, including high school research interns, undergraduate RAs, and students in undergraduate and masters level design courses. DREEMers engaged naturally with several of the concepts discussed in Chapter 1 simply by spending structured time with disability cultural media.

In this chapter, I close with a reiteration of the research questions, findings, and the significance of the dissertation. I then use findings from Chapter 2 and 3 to contextualize the method developed in Chapter 4. In addition, I cover themes of naming and translation.

5.2 Significance of Dissertation

RQ1 requires gathering information on practices used. RQ2 requires establishing pathways to teaching them. Together, the broader significance of the study includes the following [*]:

Phenomenon: This dissertation helps to establish clear pathways for technology researchers to begin equity and justice oriented work within disability communities. Knowledge surrounding daily justice oriented journeys and practices and questions otherwise comes from extracurricular exploration or mentorship.

Discipline: Involving concepts of culture and identity has been criticized

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[*] This section follows the significance format recommended within [35]

for the potential to scare newcomers away from assistive technology work more broadly. The work herein contributes to critical and justice related literature in the SIGACCESS community by bridging activism and human centered design practices as clear, actionable strategies.

World: This has the potential to help future researches make real world impact by changing what work is emphasized and how it is taken on.

5.3 Practices for Justice-Oriented Work

The primary research question I sought to uncover was: *What are common practices for technologists who do justice and equity-based work?*. In this section, I summarize the practices identified within this dissertation, as well as developed within the scope of the dissertation.

5.3.1 Practices Identified

Chapter 2 specifies three ''tools for equitable processes" that researchers can consider using based on our findings in the literature review. These include reflexivity, direct support, and justice-oriented frameworks. **Reflexivity** helps at the individual level to reflect on how larger systems of power and capital shape their research and relationships with participants. **Direct support** illustrates the time benefits researchers try to bring to their communities directly. These supports included: custom technology, financial compensation, programming, organizational capacity building, emotional benefits, and more (feedback, informatics, food, etc.). **Justice-Oriented Frameworks** are a valuable tool to decenter dominant ways of thinking and highlight alternative viewpoints. They can be used to foreground a population, a set of harms, or a specific set of values that may otherwise be marginalized in design work.

Chapter 3 outlines several practices from those interested in disability justice. These include coping with burnout, course correction, being in community with disabled people, payment, and sharing back. **Coping with burnout** was an unfortunately necessary practice for participants and often involved making difficult decisions about how best to care for oneself. Establishing techniques for **course correction** was another necessary practice due to the potential for missteps in thorny justice work. **Being in community** was not always an intentional strategy but a common practice that shaped participants' lives and work nonetheless. The **financial practice** discussed within the interviews was similar to the notion of Direct Support posited by the literature review article: a way to specifically support community members. In addition, it included making sure the most impacted people, or those who the study aims to serve, are involved in or leading your research teams. **Sharing back** was a way of making sure findings were relevant to the community in question and of community-based research direction and feedback.

5.3.2 Emergent Practices

In addition to identifying practices for justice-oriented HCI research, this dissertation puts forward new potential practices to be taken up. These include considerations for framing and approaching justice-oriented work and a method for disability enculturation before engaging with disability-related projects.

Our literature review of social justice in HCI (Chapter 2) presents a set of **5 considerations** that we use to interpret and present the corpus. This was necessary because authors did not frequently specify what they meant by social justice nor the impact of their politics on their research areas or approaches. Importantly to my dissertation, these 5 considerations also serve as a tool for future researchers doing justice-related work. Researchers can use them to frame and understand social justice issues as well as decide how to approach them. These considerations include: (1) identifying harms and benefits, (2) identifying who harms and who benefits, (3) identifying sources of harm, (4) identifying levels at which to intervene (individual, communal, or systemic) and (5) tool and method choices and their implications for justice. To support these considerations, we provide a **taxonomy of harms** from Canning and Tombs [3] that HCI researchers can use for (1). The taxonomy included physical harms, psychological and emotional harms, financial and economic harms, cultural harms, harms of recognition, and harms of autonomy. We did not find a corresponding taxonomy for benefit.

Chapter 4 is dedicated to the iterative development of a justice oriented method for engaging in disability related projects. This method is a tool for newcomers to learn the practice of ‘’Being in Community with Disabled People.” **DREEM** considers issues of labor, ways of knowing, and seeing people as whole, creators in their own right. DREEM is developed to fit into the first human centered design phase: empathy building. DREEM encourages disability enculturation rather than empathy building, which often falls into ableist traps of viewing visibility only through a deficit lens.

5.4 Teaching Practices

RQ2 asks *How do we teach these practices to HCI practitioners new to the space of disability and access?* To answer this question, I highlight the results of Chapter 3. This interview series was my primary investigation into how practitioners currently bring others into the fold of thinking about disability justice.

Interviewees highlighted the importance of teaching justice orientations to technologists (See Section 3.5.4). Technology's role in everyday life is only expanding. Participants noted that many societal systems are now technologically mediated, giving technologists the power to build or break barriers. We saw that introducing DJ to technologists was thought to give a new way of (1) seeing the world, (2) challenging dominant perspectives, and (3) acting to make change.

In addition, teaching is important in order to make more widespread forward progress. A common theme from the interviews was burnout due to getting others to care about access and disabled lives. While some labor of onboarding others into DJ thinking was part of that burnout, teaching will only make our common struggle easier by getting them to commit and make change. Convincing others that disabled people matter is an exhausting yet surprisingly constant issue. DJ practices are difficult to enact within current work systems and usually require not taking *''the path of least resistance"* -P11. But, as P17 put it: *''if someone really understands the value of this, they're gonna, they're gonna be OK with it being hard."* As P12 echoed that the *''uphill battle*" will continue if we do not bring others into the fold.

When participants themselves were learning, most did not find DJ through school or technology education contexts (See Section 3.5.1). Instead, they were introduced to concepts of DJ through community involvement on social media and beyond, personal experiences of injustice, mentorship, friends, and even from research participants.

Participants' advice for newcomers was resoundingly to listen to disabled people, whether that be in person or by deliberately engaging with books, movies, social media, and more. Making disabled culture a part of the everyday content learners engage with, committing to uncomfortable conversations, and fostering curiosity were all strategies recommended by participants. These activities are not explicitly disability justice; rather they tend toward preliminary exploration and openness to disabled experience. This finding highlights the importance of disability enculturation rather than direct, explicit or academic pursuits of disability justice as introduction for newcomers.

5.5 DREEM Contextualized

This concept of enculturation as a primary step is instrumental to DREEM. Chapter 4 outlines the design and context of this method. In this section, I contextualize DREEM based on the findings of the research studies in Chapter 2 and 3.

First, the practice of ''being in community with disabled people." Most participants discussed some aspect of being in community as being important to their everyday lives and work. However, it was not recommended that newcomers ''*manufacture*" -P6 friendships with disabled people as a means to an end. Instead, participants recommended seeking online spaces and media that disabled communities are involved in and making them a part of everyday media consumption. This practice and recommendation gives grounds for DREEM: a method that is rooted in engaging with media created by disabled people.

Next, in the discussion of the systematic literature review, we highlight the importance of moving away from deficit views. Existing empathy-building techniques for disability primarily include creating an imagined experience of disability, whether through empathy maps, personas, or disability simulations [352,356]. Simulations for disability usually revolve around taking some physical ability away from the designer, giving them a deficit view by default. Other techniques for empathy building included ethnographic work such as interviews and surveys. From the interviews, in Section 3.5.2 we saw the potential cost of asking disabled people to inform designers of basic facts of life. In contrast, DREEM has designers engage with cultural content made by people with disabilities. This uplifts existing labor, and asks researchers to unpack the real experiences and contexts of disabled life, some of which may not be related to disability at all! This emphasizes that designers should create for the fullness of disabled life.

DREEM is also supported by the work herein for its honoring disabled knowledge. Chapters 2 and 3 both highlight harm done to people related to knowledge creation and devaluing disabled/cultural ways of knowing (see Sections 2.6 and 3.5.2). The findings from the interviews refer to this as an epistemological tension. The taxonomy in Chapter 2 refers to them as either cultural harms, or harms of recognition [3]. Cultural harms are those which ‘’Destroy, undermine, or impose a particular culture.” Harms of recognition were those that ‘’Reduced, distorted, or negatively impact peoples ability to engage in society.” DREEM helps designers and researchers to recognize disabled knowledge and culture from the source. Still, because it is a first step it does not necessarily impact knowledge creation and credit downstream in projects. It can be seen as a partial response to these harms and tension.

In addition, DREEM asks designers to reflect on personal relation to the topic, and document changes in perspective. Reflexivity was important in both prior studies and is discussed further in the following section. In Chapter 2, we found that individual-level interventions were rarely documented in HCI papers. This reflexive method is a site of individual-level intervention as discussed in Section 2.7 because it intends to bring personal change and perspective shift. DREEM gives one option for HCI researchers interested in justice to act toward individual-level personal change.

5.6 Comparing Strategies

This section compares the differences and similarities between practices found in Chapter 2 and Chapter 3. That is, those that were found looking at social justice throughout HCI publications, and those that were found via discussing Disability Justice with individuals. The differences may exist due to justice domain or the medium of each study.

The Social Justice article recommends three tools: reflexivity, direct support, and justice-oriented frameworks (See Section 2.8). Justice-oriented frameworks are used ‘’to foreground a population, a set of harms, or a specific set of values.” The principles of DJ can be seen as a justice-oriented framework that foregrounds

Disabled BIPOC Queer and working-class people and values anti-capitalist politics, wholeness, collectivity, and more.

Direct support in the social justice chapter included providing custom technology, financial compensation, programming, organizational capacity building, emotional benefits, and more (feedback, informatics, food, etc.). The DJ chapter highlights providing financial support via employment and direct payments, but does not cover the other direct benefits.

The last tool recommended by the SJ paper is reflexivity (Section 2.8.1). Reflexivity as an exercise (whether public in an article or private) was also brought up as a valued practice by DJ participants (like P5 who engages in a reflexivity exercise before beginning a project). In a catalog of all reflexivity and positionality statements within our corpus, 63% of papers included membership (mis)match with the community in question. The DJ article gives ground to problematize the possibility of positionality statements containing membership being used to judge work. While we saw that people want to learn specifically from disabled people (Section 3.5.2), there was an associated tension due to the extra forms of labor required for disabled people to teach others. Additional issues arise when membership disclosure in academic articles is applied to disability. First, expecting disclosure may ‘’out” those who have invisible disabilities in permanent, archival writing. As P11 said: *‘’Theres some people who you will, youll never know if they have a invisible disability and they shouldn’t be required to disclose it in order to do this work.”* Second, it may trivialize the double-anonymized peer review process where disabled authors are known to the community. In addition, disabled ‘’identities are potentially evolving spaces for individuals” and may not be static or fully formed at the time of writing (see Section 3.5.2 on Identity, Disclosure, Labor). Reflexivity in the SJ article is recommended as a method of engaging in ‘’personal work,” to identify and work through personal biases [252]. It is clear that reporting membership (as more than half of articles with positionality/reflexivity statements did) has complications for researchers with historically marginalized identities when that personal work is expected to be shown in the public square [*].

The literature review offers levels of intervention (individual, communal, systemic) to help researchers decide where to act. When discussing dreams of the future (Section 3.6), interview participants dreamed of intervention and change at all levels. This included individual (*‘’If I really want to pursue disability justice, shouldn't I live it also for myself?”*-P14), communal (*‘’We should all be in a group togetherThere's nobody really to go to, to answer this stuff.”* -P12), something between communal and systemic (*‘’even while we change the system, we need to make the system better for the people that are already here.”* -P9), and systemic (*‘’if I could overhaul society, I would”*-P15).

In terms of harms (see Section 2.6) those explored in the DJ section were mostly limited to cultural harms and harms of recognition. Strategies that were present in the interview study but not the literature review included ‘’course correction” and ‘’being in community with disabled people.” Future work might explore what impact these practices have on other forms of harm. For example, what does ‘’being in community” look like when intervening on environmental harms?

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[*] For further reading: a new article by Gani and Khan has come out in the week of filing this dissertation. It offers valuable documentation of positionality "as a Function of Coloniality." [431]

Similarities between the studies include labor and flourishing. Both chapters cover the concept of additional labor for people working in this space, and SJ suggests research reform to honor the additional work required for justice orientations. An additional similarity includes moving away from a productivity lens (DJ Chapter) and toward flourishing and joy (both Chapters).

5.7 Personal Journey

In this dissertation, I report on the state of social justice in HCI and justice-oriented practices for engineers and designers working with disabled communities. This work has been motivated by my own journey from engineering undergraduate until now. In this section, I briefly reflect on my own journey, and how this work has influenced me.

The phrase ''this work" includes so many things. On this journey, I've learned from so many sources including classmates and instructors in my time in the PhD program at UC Santa Cruz, mentorship from advisors and academic community members, collaborators, lab mates, book club members, my partner, friends, disabled cultural creators, and discord servers where I spent time figuring it out with other chronically ill people, ND people, and graduate students. Experiences with these people and groups have helped me learn more about DJ, HCI, and myself. They have given me words for experiences I've had. They have helped me on my own journey with disabled identity. After writing this section, I read Nicole Lee Schroeder's Unspooling [432], in Disability Intimacy [348][*]. It describes this so

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[*] As both a weaver and a chronically ill person, I am so excited to have read this essay.

much better than I could here:

> *‘’These days, I weave disabled love into my life like a practiced artisan. I spin threads of love from late-night phone calls, Zoom get-togethers, and disparate Twitter threads. Hand over hand, I wind up scraps of wisdom from those who’ve come before me. I weave line after line, watching as patterns spring into existence, crafted from the instructions they have patiently and lovingly written down.”* [432]

This work has pulled me out of my comfort zone in so many ways. It has made me think critically in a way I did not know how to before. It has made me write in ways that feel vulnerable and scary, engaging in critique and reflection rather than focusing on technical reports. Writers seem so sure of themselves when I read critique work. The process has been anything but sure for me, second-guessing many steps and only getting through it by talking with others and sitting for a long time with ideas. It is so much slower than technical writing. Beyond the writing, the work itself has been very vulnerable as it’s something I care deeply about and identify with. Even less comfortable: aspects of this work have the potential for people to feel called out and for me to be extractive and coopting. In a journal entry dated 9/30/22 I write:

> *‘’am I doing enough? Will I be able to get my degree on time? Is the work that I’m doing right? It’s all very scary for some reason. I feel like I’m putting myself out there for everyone to see and I feel very vulnerable.”*

It has been vulnerable to go through my processing publicly, knowing that I'm only at one stage of my journey. I have likely have gotten things wrong. Although it feels self-aggrandizing, I hope that at least by documenting this strange journey, readers will feel ok with anything theirs looks like!

5.7.1 Challenges and Looking Forward

This work has been done over the course of an extremely challenging time throughout global, community, and personal events. Even from my extremely privileged position, it was difficult to manage in the state of the world. From dealing with my own illness and navigating medical systems, to wider societal issues. Calls for justice have been extraordinarily regular due to events throughout my 6-year PhD.

Engaging with disability and justice in a work and study context was sometimes too much for me. In a journal dated 10/14/22 while waiting to hear news of a medical procedure, and working on a PhD milestone for my program I write:

> *''the only books I have right now are disability and activism related and that's too much for me to process right now."*

Throughout all of this, I also had to engage with the shortcomings of academic research. I am so thankful to have ended with the DJ interviews. Although I was the one asking the questions, it was healing to speak with others who were having similar experiences with academia and their work.

I've been dragging my feet on writing this section because I feel like it has to be perfect and thoughtful and illustrate all the places I've been, where I'm going, and why. But I still don't know where I'm going. Next, at least, I know I will try for some time away from academia. In a journal dated 4/18/24 I write: *''[redacted] brought up how academia forces you to need to be someone."* This mirrors what I was told coming into the program - that by the time you are awarded a PhD, you should be widely recognized as the expert in your domain space. This is in complete opposition to DJ which values ''Leadership of the most impacted," not those in the ivory tower. I'm tired due to all of the tensions listed in Section 3.5.2, and ready to exit for a time. In a journal dated 10/20/23 I write:

> *''It was really good to be doing something non-academic... [community] is the reason all the academic stuff matters, but [researcher impact] rarely makes it out of the academic bubble."*

I'm looking forward to being present and having time for myself, those close to me, and my community.

5.8 Closing Thoughts

The work herein barely scratches the surface of possibility. Concepts of justice are concerned with thwarting harms against people, cultures, and the environment in order to build toward better futures. These aims fit well with those of HCI, which generally has the goal of understanding and building for people, especially in future-facing technology development. In Sections 1.5, and 3.7.1 of this dissertation, I discuss the evolution of AT and accessibility research toward valuing critical reasoning, situated knowledge, and design for leisure. In addition, the latter charts the rise in acknowledgment of ableism within society. The evolution of accessibility research is ongoing, and tending toward justice. When it comes down to it, valuing disabled lives and fighting for our collective liberations does not seem that radical, and certainly not far from HCI's future building and human-centered values. This contribution outlines journeys and provides a variety of practices researchers can use to work toward just futures. I look forward to the possibilities to come!

Technologists have the power to build or break barriers. Lets choose to work toward liberation.

Appendix

.1 Social Justice in HCI: Corpus at a Glance

.1.1 Publication Venues

The first instances of social justice-oriented papers in our corpus originated from CHI in 2009 (See Figure 2.2). We see the topic begin to gain momentum after 2016, following a foundational publication from Dombrowski et al. introducing *social justice-oriented interaction design.* Publication numbers also seem to follow larger social, cultural, and political conditions. There is evident growth following 2020 which aligns with the Black Lives Matter protests and the COVID-19 pandemic. Similarly, a period of growth happened in 2017 and 2018, which may relate to the #MeToo movement. When we conducted our search, CSCW publications had not been released yet for 2022. Overall, CHI has the most contributions (n=92) to our corpus, followed by DIS (n=23) and CSCW (n=8). UbiCOMP has only one contribution in our corpus [186]. It follows that the low incidence of papers from UbiCOMP might be explained by the conference's focus on devices and technology development. However, ubiquitous computing revolves around computing in our everyday lives - it seems that this area should be a great fit for social justice-oriented research. As discussed in the next sections, we saw a low incidence of papers that engaged in technology development and or within the domain of emerging technologies.

.1.2 Contribution Types

Wobbrock and Kientz define HCI contribution types as empirical, artifact, methodological, theoretical, dataset, survey, or opinion [433]. We coded for these contri-

Alt:*A bar graph that measures the number of papers by contribution type. From smallest to largest they are: Dataset 0, Opinion less than 5, survey slightly more than 5. Methodological theoretical and artifact are each slightly more than 10. Interviews about 60.*

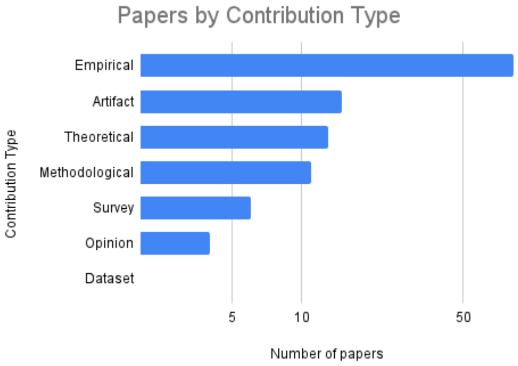

Figure 1: Contribution Types in Our Corpus

bution types directly. The most common research contribution type in our corpus was empirical work (See Figure 1). Of the papers included in our corpus, 83 made empirical contributions, 15 contributed artifacts, 13 made theoretical contributions, 11 made methodological contributions, 6 were survey studies, 4 were opinion pieces, and 2 were dataset contributions. The glaring difference between empirical contributions and others (5x more) highlights the exploratory landscape of the corpus, rather than oriented towards defining (theory) or actualizing (artifact, dataset). This exploration could represent either that the topic is still emerging within the field (following the design approach of exploring, defining, and then designing in sequence), or that empirical work is somehow better suited to social justice at this junction.

.1.3 Domains

Half of our corpus is represented by the civic technology and social computing domains (See Figure 2). There were considerably fewer paper that had to do with emerging technologies such as VR (1)[216], IoT (2) [226, 324], or AI & ML (9)[207, 261, 434]. It is surprising that these domains are not explicitly discussing social justice concerns given that these emerging technologies are reshaping the social structures we live in today.

.1.4 Methodologies Used

The most employed data collection strategies were interviews (n=53), research through design (n=23), and workshops (n=22) (see Figure 3). Many projects employed a mix of methods (n=51). Very few included gathering data from device usage like biometric data (n=2) [435], logfiles (n=4)[205], or even web scraping (n=3)[220]. One standout (though still limited) category was those who created and ran community events (n=5) as sites for data collection and observations (n=19). We highlight these papers for their efforts to organize community within the research context. For example, Rankin and Han's game nights (further discussed in Section 2.8.3), and Strohmayer et al's collaboration in organizing a public activist march on International Day to End Violence Against Sex Workers.

Alt: *A pie chart of the domain spaces. From smallest to largest by percent: privacy 1.8, accessibility 1.8, games and play 2.7, education 5.5, AI and ML 7.3, Health 8.2, Design and Methods 8.2, ICT4D 10.9, Social Computing 24.5, Civic Technology 25.5*

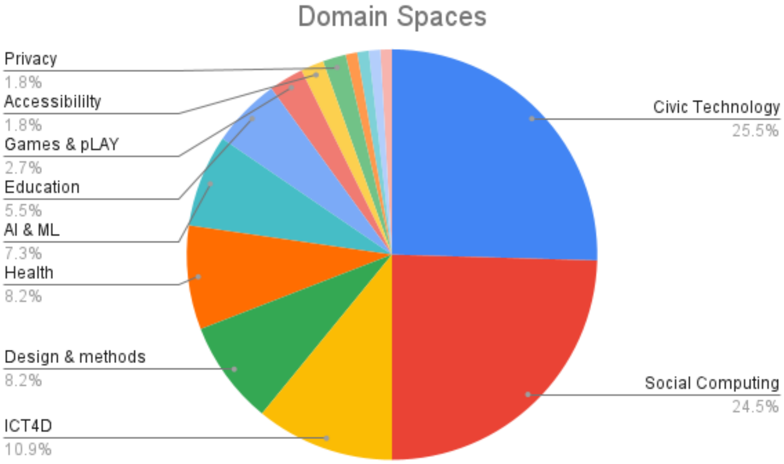

Figure 2: Domain spaces represented in our corpus

Alt: *Figure 6 is a bar graph that measures the number of papers that used certain methodologies for data collection. The highest is Interviews in more than 50 papers. All others are in nearly 20 papers: research through design, workshops, observations, surveys, field work. The remaining are used in 7 or less. They include focus groups, experiments, autoethnography, community events, literature review, logfiles, webscraping, diary studies, cultural & Discourse analysis, biometric, and cultural probes.*

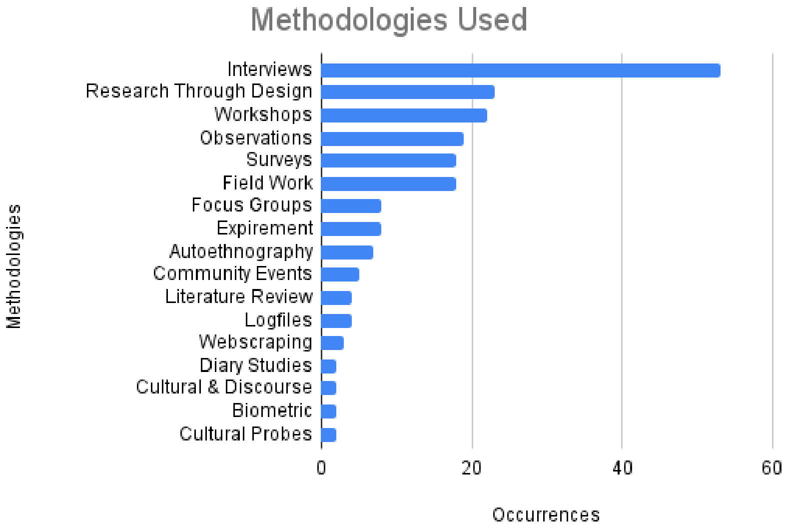

Figure 3: Types of methods used across social justice papers

.2 Social Justice in HCI: Corpus List

Table 1: A full collection of papers included in our corpus.

Title	**Authors**	**Year**	**Con**
Collaborative identity decolonization as reclaiming narrative agency: Identity work of bengali communities on quora	Das, Dipto; Semaan, Bryan	2022	CHI
Addressing age-related bias in sentiment analysis	Diaz, Mark; Johnson, Isaac; Lazar, Amanda; Piper, Anne Marie; Gergle, Darren	2018	CHI
Re-shape: A method to teach data ethics for data science education	Shapiro, Ben Rydal; Meng, Amanda; O'Donnell, Cody; Lou, Charlotte; Zhao, Edwin; Dankwa, Bianca; Hostetler, Andrew	2020	CHI
Feminist living labs as research infrastructures for HCI: The case of a video game company	Ahmadi, Michael; Eilert, Rebecca; Weibert, Anne; Wulf, Volker; Marsden, Nicola	2020	CHI

ShishuShurokkha: A transformative justice approach for combating child sexual abuse in bangladesh	Sultana, Sharifa; Pritha, Sadia Tasnuva; Tasnim, Rahnuma; Das, Anik; Akter, Rokeya; Hasan, Shaid; Alam, S.M. Raihanul; Kabir, Muhammad Ashad; Ahmed, Syed Ishtiaque	2022	CHI
Examining the intersections of race, religion & community technologies: A photovoice study	O'Leary, Teresa K.; Stowell, Elizabeth; Hoffman, Jessica A.; Paasche-Orlow, Michael; Bickmore, Timothy; Parker, Andrea G.	2021	CHI
Crafting everyday resistance through lightweight design	Fox, Sarah E.; Shorey, Samantha; Spektor, Franchesca; Rosner, Daniela K.	2020	DIS
Ways of knowing when research subjects care	Howard, Dorothy; Irani, Lilly	2019	CHI
Wanting to live here: Design after anthropocentric functionalism	Bardzell, Jeffrey; Bardzell, Shaowen; Light, Ann	2021	CHI

Sensemaking, support, safety, retribution, transformation: A restorative justice approach to understanding adolescents needs for addressing online harm	Xiao, Sijia; Cheshire, Coye; Salehi, Niloufar	2022 CHI
Opening research commissioning to civic participation: Creating A community panel to review the social impact of HCI research proposals	G Johnson, Ian; Crivellaro, Clara	2021 CHI
Can I not be suicidal on a sunday?: Understanding technology-mediated pathways to mental health support	Pendse, Sachin R; Sharma, Amit; Vashistha, Aditya; De Choudhury, Munmun; Kumar, Neha	2021 CHI
Techniques of use: Confronting value systems of productivity, progress, and usefulness in computing and design	Lin, Cindy; Margot Lindtner, Silvia	2021 CHI
The critical catalog: Library information systems, tricksterism, and social justice	Clarke, Rachel Ivy; Schoonmaker, Sayward	2020 CHI

Transforming last-mile logistics: Opportunities for more sustainable deliveries	Bates, Oliver; Friday, Adrian; Allen, Julian; Cherrett, Tom; McLeod, Fraser; Bektas, Tolga; Nguyen, ThuBa; Piecyk, Maja; Piotrowska, Marzena; Wise, Sarah; Davies, Nigel	2018	CHI
Engaging gentrification as a social justice issue in HCI	Corbett, Eric; Loukissas, Yanni	2019	CHI
Illegitimate civic participation: Supporting community activists on the ground	Asad, Mariam; Le Dantec, Christopher A.	2015	CSCW
Understanding AR activism: An interview study with creators of augmented reality experiences for social change	Silva, Rafael M. L.; Principe Cruz, Erica; Rosner, Daniela K.; Kelly, Dayton; Monroy-Hernández, Andrés; Liu, Fannie	2022	CHI
Others' images: Online social media, architectural improvisations, and spatial marginalization in bangladesh	Mim, Nusrat Jahan; Ahmed, Syed Ishtiaque	2020	CHI

Designing trans technology: Defining challenges and envisioning community-centered solutions	Haimson, Oliver L.; Gorrell, Dykee; Starks, Denny L.; Weinger, Zu	2020	CHI
From margins to seams: Imbrication, inclusion, and torque in the aadhaar identification project	Singh, Ranjit; Jackson, Steven J.	2017	CHI
(Re)Politicizing digital well-being: Beyond user engagements	Docherty, Niall; Biega, Asia J.	2022	CHI
Technologies for social justice: Lessons from sex workers on the front lines	Strohmayer, Angelika; Clamen, Jenn; Laing, Mary	2019	CHI
Infrastructuring the imaginary: How sea-level rise comes to matter in the san francisco bay area	Soden, Robert; Kauffman, Nate	2019	CHI
Algorithmic mediation in group decisions: Fairness perceptions of algorithmically mediated vs. Discussion-based social division	Lee, Min Kyung; Baykal, Su	2017	CSCW

Navigating the job search as a low-resourced job seeker	Wheeler, Earnest; Dillahunt, Tawanna R.	2018	CHI
The cost of culture: An analysis of cash app and the financial inclusion of black american communities	Cunningham, Jay L.; Nguyen, Sydney T.; Kientz, Julie A.; Rosner, Daniela	2022	DIS
Going gray, failure to hire, and the ick factor: Analyzing how older bloggers talk about ageism	Lazar, Amanda; Diaz, Mark; Brewer, Robin; Kim, Chelsea; Piper, Anne Marie	2017	CSCW
Prioritizing flexibility and intangibles: Medical crowdfunding for stigmatized individuals	Gonzales, Amy; Fritz, Nicole	2017	CHI
Rethinking menstrual trackers towards period-positive ecologies	Tuli, Anupriya; Singh, Surbhi; Narula, Rikita; Kumar, Neha; Singh, Pushpendra	2022	CHI
Puget sound off: Fostering youth civic engagement through citizen journalism	Farnham, Shelly; Keyes, David; Yuki, Vicky; Tugwell, Chris	2012	CSCW
Troubling vulnerability: Designing with LGBT young people's ambivalence towards hate crime reporting	Gatehouse, Cally; Wood, Matthew; Briggs, Jo; Pickles, James; Lawson, Shaun	2018	CHI

Digital portraits: Photo-sharing after domestic violence	Clarke, Rachel; Wright, Peter; Balaam, Madeline; McCarthy, John	2013	CHI
All that you touch, you change: Expanding the canon of speculative design towards black futuring	Harrington, Christina N.; Klassen, Shamika; Rankin, Yolanda A.	2022	CHI
Culture in action: Unpacking capacities to inform assets-based design	Wong-Villacres, Marisol; DiSalvo, Carl; Kumar, Neha; DiSalvo, Betsy	2020	CHI
Community historians: Scaffolding community engagement through culture and heritage	Fox, Sarah; Le Dantec, Christopher	2014	DIS
A human-centered approach to algorithmic services: Considerations for fair and motivating smart community service management that allocates donations to non-profit organizations	Lee, Min Kyung; Kim, Ji Tae; Lizarondo, Leah	2017	CHI
Queuing for waste: Sociotechnical interactions within a food sharing community	Berns, Katie; Rossitto, Chiara; Tholander, Jakob	2021	CHI

The politics of measurement and action	Pine, Kathleen H.; Liboiron, Max	2015	CHI
The village: Infrastructuring community-based mentoring to support adults experiencing poverty	Dillahunt, Tawanna R; Lu, Alex Jiahong; Israni, Aarti; Lodha, Ruchita; Brewer, Savana; Robinson, Tiera S; Wilson, Angela Brown; Wheeler, Earnest	2022	CHI
A vehicle for research: Using street sweepers to explore the landscape of environmental community action	Aoki, Paul M.; Honicky, R. J.; Mainwaring, Alan; Myers, Chris; Paulos, Eric; Subramanian, Sushmita; Woodruff, Allison	2009	CHI
The polyvocality of online COVID-19 vaccine narratives that invoke medical racism	Diamond, Lindsay Levkoff; Batan, Hande; Anderson, Jennings; Palen, Leysia	2022	CHI

Unmochon: A tool to combat online sexual harassment over facebook messenger	Sultana, Sharifa; Deb, Mitrasree; Bhattacharjee, Ananya; Hasan, Shaid; Alam, S.M.Raihanul; Chakraborty, Trishna; Roy, Prianka; Ahmed, Samira Fairuz; Moitra, Aparna; Amin, M Ashraful; Islam, A.K.M. Najmul; Ahmed, Syed Ishtiaque	2021 CHI
Reducing uncertainty and offering comfort: Designing technology for coping with interpersonal racism	To, Alexandra; Carey, Hillary; Kaufman, Geoff; Hammer, Jessica	2021 CHI
DanceON: Culturally responsive creative computing	Payne, William Christopher; Bergner, Yoav; West, Mary Etta; Charp, Carlie; Shapiro, R. Benjamin Benjamin; Szafir, Danielle Albers; Taylor, Edd V.; DesPortes, Kayla	2021 CHI
Gender norms and attitudes about childcare activities presented on father blogs	Lukoff, Kai; Moser, Carol; Schoenebeck, Sarita	2017 CHI

HCI and environmental sustainability: The politics of design and the design of politics	Dourish, Paul	2010	DIS
Social computing-driven activism in youth empowerment organizations: Challenges and opportunities	Irannejad Bisafar, Farnaz; Martinez, Lina Itzel; Parker, Andrea G.	2018	CHI
Speculative blackness: Considering afrofuturism in the creation of inclusive speculative design probes	Bray, Kirsten; Harrington, Christina	2021	DIS
Social justice-oriented interaction design: Outlining key design strategies and commitments	Dombrowski, Lynn; Harmon, Ellie; Fox, Sarah	2016	DIS
Inclusion at scale: Deploying a community-driven moderation intervention on twitch	Brewer, Johanna; Romine, Morgan; Taylor, T. L.	2020	DIS
Accessibility and the crowded sidewalk: Micromobility's impact on public space	Bennett, Cynthia; Ackerman, Emily; Fan, Bonnie; Bigham, Jeffrey; Carrington, Patrick; Fox, Sarah	2021	DIS

Whither humane-computer interaction? Adult and child value conflicts in the biometric fingerprinting for food	Mudliar, Preeti	2020	CHI
Co-designing digital platforms for volunteer-led migrant community welfare support	Seguin, Joshua Paolo; Varghese, Delvin; Anwar, Misita; Bartindale, Tom; Olivier, Patrick	2022	DIS
AI in global health: The view from the front lines	Ismail, Azra; Kumar, Neha	2021	CHI
Negotiating sustainable futures in communities through participatory speculative design and experiments in living	Chopra, Simran; Clarke, Rachel E; Clear, Adrian K; Heitlinger, Sara; Dilaver, Ozge; Vasiliou, Christina	2022	CHI
Hollaback! The role of storytelling online in a social movement organization	Dimond, Jill P.; Dye, Michaelanne; Larose, Daphne; Bruckman, Amy S.	2013	CSCW
A study of urban heat: Understanding the challenges and opportunities for addressing wicked problems in HCI	Kuznetsov, Stacey; Tomitsch, Martin	2018	CHI

Keeper: A synchronous online conversation environment informed by in-person facilitation practices	Hughes, Margaret A.; Roy, Deb	2021	CHI
Designing within capitalism	Wolf, Christine T.; Asad, Mariam; Dombrowski, Lynn S.	2022	DIS
Participatory memory making: Creating postcolonial dialogic engagements with namibian youth	Kambunga, Asnath Paula; Winschiers-Theophilus, Heike; Smith, Rachel Charlotte	2020	DIS
Postcolonial computing: A lens on design and development	Irani, Lilly; Vertesi, Janet; Dourish, Paul; Philip, Kavita; Grinter, Rebecca E.	2010	CHI
Feminist HCI: Taking stock and outlining an agenda for design	Bardzell, Shaowen	2010	CHI
ADHD and technology research investigated by neurodivergent readers	Spiel, Katta; Hornecker, Eva; Williams, Rua Mae; Good, Judith	2022	CHI
Technologies and social justice outcomes in sex work charities: Fighting stigma, saving lives	Strohmayer, Angelika; Laing, Mary; Comber, Rob	2017	CHI

Biographies of biometric devices: The POS machine at work in india’s PDS	Mudliar, Preeti	2021	CHI
Freaky: Performing hybrid human-machine emotion	Leahu, Lucian; Sengers, Phoebe	2014	DIS
Moving for the movement: Applying viewpoints and composition techniques to the design of online social justice campaigns	Oden Choi, Judeth; Hammer, Jessica; Royal, Jon; Forlizzi, Jodi	2020	DIS
A qualitative exploration of perceptions of algorithmic fairness	Woodruff, Allison; Fox, Sarah E.; Rousso-Schindler, Steven; Warshaw, Jeffrey	2018	CHI
"We Come Together as One...and Hope for Solidarity to Live on": On designing technologies for activism and the commemoration of lost lives	Strohmayer, Angelika; Meissner, Janis Lena; Wilson, Alexander; Charlton, Sarah; McIntyre, Laura	2020	DIS
Interactive fiction provotypes for coping with interpersonal racism	To, Alexandra; Carey, Hillary; Shrivastava, Riya; Hammer, Jessica; Kaufman, Geoff	2022	CHI

Training and embedding cybersecurity guardians in older communities.	Nicholson, James; Morrison, Ben; Dixon, Matt; Holt, Jack; Coventry, Lynne; McGlasson, Jill	2021	CHI
This changes sustainable HCI	Knowles, Bran; Bates, Oliver; Håkansson, Maria	2018	CHI
Situated encounters with socially engaged art in community-based design	Clarke, Rachel; Briggs, Jo; Light, Ann; Wright, Pete	2016	DIS
Healing justice: A framework for collective healing and well-being from systemic traumas	Bosley, Brooke; Harrington, Christina N.; Morris, Susana M.; Le Dantec, Christopher A.	2022	DIS
Beyond the prototype: Maintenance, collective responsibility, and public IoT	Fox, Sarah E.; Silva, Rafael M.L.; Rosner, Daniela K.	2018	DIS
It takes more than one hand to clap: On the role of Care in maintaining design results.	Krüger, Max; Weibert, Anne; Leal, Debora de Castro; Randall, Dave; Wulf, Volker	2021	CHI
Selling glossy, easy futures: A feminist exploration of commercial mental-health-focused self-care apps descriptions in the google play store	Spors, Velvet; Wagner, Hanne Gesine; Flintham, Martin; Brundell, Pat; Murphy, David	2021	CHI

Unmaking as agonism: Using participatory design with youth to surface difference in an intergenerational urban context	Sabie, Samar; Jackson, Steven J.; Ju, Wendy; Parikh, Tapan	2022	CHI
FollowBias: Supporting behavior change toward gender equality by networked gatekeepers on social media	Matias, J. Nathan; Szalavitz, Sarah; Zuckerman, Ethan	2017	CSCW
Armed in ARMY: A case study of how BTS fans successfully collaborated to #MatchAMillion for black lives matter	Park, So Yeon; Santero, Nicole K.; Kaneshiro, Blair; Lee, Jin Ha	2021	CHI
"Genderfluid" or "Attack Helicopter": Responsible HCI research practice with non-binary gender variation in online communities	Jaroszewski, Samantha; Lottridge, Danielle; Haimson, Oliver L.; Quehl, Katie	2018	CHI
Getting ourselves together: Data-centered participatory design research & epistemic burden	Pierre, Jennifer; Crooks, Roderic; Currie, Morgan; Paris, Britt; Pasquetto, Irene	2021	CHI
The care work of access	Bennett, Cynthia L.; Rosner, Daniela K.; Taylor, Alex S.	2020	CHI

Mapping the margins: Navigating the ecologies of domestic violence service provision	Bellini, Rosanna; Strohmayer, Angelika; Olivier, Patrick; Crivellaro, Clara	2019	CHI
Cultivating care through ambiguity: Lessons from a service learning course	Sabie, Samar; Parikh, Tapan	2019	CHI
Its complicated: Negotiating accessibility and (Mis)Representation in image descriptions of race, gender, and disability	Bennett, Cynthia L.; Gleason, Cole; Scheuerman, Morgan Klaus; Bigham, Jeffrey P.; Guo, Anhong; To, Alexandra	2021	CHI
Identity work as deliberation: AAPI political discourse in the 2016 US presidential election	Dosono, Bryan; Semaan, Bryan	2018	CHI
Facebook in venezuela: Understanding solidarity economies in low-trust environments	Evans, Hayley I.; Wong-Villacres, Marisol; Castro, Daniel; Gilbert, Eric; Arriaga, Rosa I.; Dye, Michaelanne; Bruckman, Amy	2018	CHI
A systematic review and thematic analysis of community-collaborative approaches to computing research	Cooper, Ned; Horne, Tiffanie; Hayes, Gillian R; Heldreth, Courtney; Lahav, Michal; Holbrook, Jess; Wilcox, Lauren	2022	CHI

Making as expression: Informing design with people with complex communication needs through art therapy	Lazar, Amanda; Feuston, Jessica L.; Edasis, Caroline; Piper, Anne Marie	2018	CHI
Trauma-informed computing: Towards Safer Technology Experiences for All	Chen, Janet X.; McDonald, Allison; Zou, Yixin; Tseng, Emily; Roundy, Kevin A; Tamersoy, Acar; Schaub, Florian; Ristenpart, Thomas; Dell, Nicola	2022	CHI
What can HCI learn from sexual consent? A feminist process of embodied consent for interactions with emerging technologies	Strengers, Yolande; Sadowski, Jathan; Li, Zhuying; Shimshak, Anna; 'Floyd' Mueller, Florian	2021	CHI
Coding bias in the use of behavior management technologies: Uncovering socio-technical consequences of data-driven surveillance in classrooms	Lu, Alex Jiahong; Marcu, Gabriela; Ackerman, Mark S.; Dillahunt, Tawanna R	2021	DIS
Food democracy in the making: Designing with local food networks	Prost, Sebastian; Crivellaro, Clara; Haddon, Andy; Comber, Rob	2018	CHI

Making crafting visible while rendering labor invisible on the etsy platform	Razaq, Lubna; Kolko, Beth; Hsieh, Gary	2022	DIS
Not just a preference: Reducing biased decision-making on dating websites	Ma, Zilin; Gajos, Krzysztof Z.	2022	CHI
Designing civic technology with trust	Corbett, Eric; Le Dantec, Christopher	2021	CHI
Experiences of harm, healing, and joy among black women and femmes on social media	Musgrave, Tyler; Cummings, Alia; Schoenebeck, Sarita	2022	CHI
The psychological well-being of content moderators: The emotional labor of commercial moderation and avenues for improving support	Steiger, Miriah; Bharucha, Timir J; Venkatagiri, Sukrit; Riedl, Martin J.; Lease, Matthew	2021	CHI
The larger picture: A designerly approach to making the invisible domestic workloads of working women visible	Dhaundiyal, Dhriti; Pai, Sanket; Cramer, Mechthild; Buchmueller, Sandra; Malhotra, Sugandh; Bath, Corinna	2021	CHI
Biographical prototypes: Reimagining recognition and disability in design	Bennett, Cynthia L.; Peil, Burren; Rosner, Daniela K.	2019	CHI

Resisting the medicalisation of menopause: Reclaiming the body through design	Ciolfi Felice, Marianela; Søndergaard, Marie Louise Juul; Balaam, Madeline	2021	CHI
HCI tactics for politics from below: Meeting the challenges of smart cities	Whitney, Cedric Deslandes; Naval, Teresa; Quepons, Elizabeth; Singh, Simrandeep; Rick, Steven R; Irani, Lilly	2021	CHI
Ubicomp's colonial impulse	Dourish, Paul; Mainwaring, Scott D.	2012	CSCW
A second voice: Investigating opportunities and challenges for interactive voice assistants to support home health aides	Bartle, Vince; Lyu, Janice; El Shabazz-Thompson, Freesoul; Oh, Yunmin; Chen, Angela Anqi; Chang, Yu-Jan; Holstein, Kenneth; Dell, Nicola	2022	CHI
"We Can Learn. Why Not?": Designing technologies to engender equity for home health aides	Tseng, Emily; Okeke, Fabian; Sterling, Madeline; Dell, Nicola	2020	CHI
Diagnosing bias in the gender representation of HCI research participants: How it happens and where we are	Offenwanger, Anna; Milligan, Alan John; Chang, Minsuk; Bullard, Julia; Yoon, Dongwook	2021	CHI

Attenuated access: Accounting for startup, maintenance, and affective costs in resource-constrained communities	Pei, Lucy; Crooks, Roderic	2020	CHI
Its like a GPS community tool: Tactics to foster digital commons through artifact ecology	Bettega, Mela; Masu, Raul; Teli, Maurizio	2021	DIS
The hidden language of vibrators: A politico-ontological reading	Hua, Dianya Mia; Jones, Rhys; Bardzell, Jeffrey; Bardzell, Shaowen	2022	DIS
A feminist utopian perspective on the practice and promise of making	Okerlund, Johanna; Wilson, David; Latulipe, Celine	2021	CHI
Unpacking the complexities of community-led violence prevention work	Erete, Sheena; Dickinson, Jessa; Gonzalez, Alejandra C.; Rankin, Yolanda A.	2022	CHI
Hackathons as participatory design: Iterating feminist utopias	Hope, Alexis; D'Ignazio, Catherine; Hoy, Josephine; Michelson, Rebecca; Roberts, Jennifer; Krontiris, Kate; Zuckerman, Ethan	2019	CHI
Human-computer insurrection: Notes on an anarchist HCI	Keyes, Os; Hoy, Josephine; Drouhard, Margaret	2019	CHI

Money whispers: Informality, international politics, and immigration in transnational finance	Rohanifar, Yasaman; Chandra, Priyank; Rahman, M Ataur; Ahmed, Syed Ishtiaque	2021	CHI
Exploring the plurality of black women's gameplay experiences	Rankin, Yolanda A.; Han, Naeun	2019	CHI
It cannot do all of my work: Community health worker perceptions of AI-Enabled mobile health applications in rural india	Okolo, Chinasa T.; Kamath, Srujana; Dell, Nicola; Vashistha, Aditya	2021	CHI
#Indigenous: Tracking the connective actions of native american advocates on twitter	Vigil-Hayes, Morgan; Duarte, Marisa; Parkhurst, Nicholet Deschine; Belding, Elizabeth	2017	CSCW
Priorities, technology, & power: Co-designing an inclusive transit agenda in kampala, uganda	Kirabo, Lynn; Carter, Elizabeth Jeanne; Barry, Devon; Steinfeld, Aaron	2021	CHI
Parting the red sea: Sociotechnical systems and lived experiences of menopause	Lazar, Amanda; Su, Norman Makoto; Bardzell, Jeffrey; Bardzell, Shaowen	2019	CHI

(Re)Discovering the physical body online: Strategies and challenges to approach non-cisgender identity in social virtual reality	Freeman, Guo, Divine Maloney, Dane Acena, and Catherine Barwulor.	2022	CHI
Strangers at the gate: Gaining access, building rapport, and co-constructing community-based research	Le Dantec, Christopher A.; Fox, Sarah	2015	CSCW
On activism and academia: Reflecting together and sharing experiences among critical friends	Leal, Debora de Castro; Strohmayer, Angelika; Krüger, Max	2021	CHI

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