Challenging Ableism:

A critical turn toward disability justice in HCI

A reflection on our learnings from the CHI 2022 "Dreaming Disability Justice in HCI" workshop, and why we continue to call for disability justice, despite the limitations of how we practice it within academia and industry.

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HCI, as a field, continues to devalue the expertise of disabled people. We see this in the many HCI studies targeted at the general population that outright exclude, medicalize, and pathologize disabled people, and instead consult so-called "proxies" such as parents, caregivers, or doctors, as substitutes under the guise of "inclusion" [1]. Disabled people's multi-faceted identities and lived experiences are not well represented in the field, with less than one percent of accessibility research engaging those with multiple disabilities [2], let alone intersections of disability with race, gender, sexuality,

and class [3]. Accessibility, if included, often comes last in a project timeline, leaving disabled people with inaccessible and ineffective technologies. When disability and accessibility are a focus, the devices researchers make are primarily focused on "fixing" or "helping" disabled people through unsolicited, unwanted, and harmful technocentric interventions [4]. Scholar and activist

Liz Jackson calls these projects "disability dongles," which she defines as "well-intended, elegant, yet useless solutions to problems disabled people never knew they had" [5].

Disability dongles are everywhere. Assistive technology hackathons continually produce "intelligent" canes with Bluetooth integration, GPS navigation, and obstacle detection, but

not waterproofing—overlooking that blind people would use them outside [6]. There have been multiple attempts at creating wearable sign language-translation gloves, all of which have made the false assumption that sign language lives in the hands alone [7]. After an initial market failure targeted toward general able-bodied consumers, Google Glass has recently

been adapted to "help" autistic children perform neurotypical eye contact for an outward appearance of "normalcy" [8]. Outside of accessibility, we see algorithmic management systems that track productivity, penalize and discriminate against disabled workers who need to take more frequent breaks, and risk assessment algorithms used for policing that disproportionately target disabled people of color [9].

Spanning erasure and outright harm, these technical "innovations" represent subtle but deeply rooted ableism within our field of HCI. Talila A. Lewis, abolitionist community lawyer, educator, and organizer, defines ableism as a "system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness," [10] a form of oppression that is further reified through a Western technocratic ethos [11]. Uninterrogated, this ethos unwittingly forecloses possibilities for real justice for disabled people. Now, as accessibility research is witnessing the beginnings of a critical turn [12], we hope to recuperate critical scholarship that engages with disability in the Majority World/Global South and expand HCI's gaps as "WEIRD"-dominated (Western, educated, industrialized, rich, and democratic) field [13].

In 2022, the "Dreaming Disability Justice in HCI" workshop brought together researchers, designers, practitioners, and activists—disabled and non-disabled—across the globe [14]. We explored issues around ableism within our field while drawing upon disability justice to achieve three goals: to enrich critical HCI scholarship, to challenge Western, white, and ableist hegemonies, and to acknowledge disability in all facets of HCI.

WHAT IS DISABILITY JUSTICE?

"We are powerful not despite the complexities of our bodies, but because of them."—Sins Invalid 2016 [15]

Disability justice is a social justice movement dedicated to understanding and undoing ableism as it is affected by multiple intersectional oppressions: race, gender, and socioeconomic class [15]. The movement was initially conceived by Bay Area organizers and activists of color, including activists Patty Berne, Mia Mingus, Stacey Milbern, Leroy F. Moore Jr., Eli Clare, and Sebastian Margaret, who sought an alternative to the white-dominated and single-issue focus of the disability rights movement. In 2005, these activists' vision grew into the Disability Justice Collective, an intersectional movement that seeks to 'center the lives, needs, and organizing strategies of disabled queer and trans and/or Black and brown people marginalized from mainstream disability rights organizing [16].

Disability Justice's QTBIPOC-led praxis offers several concrete tenets [15], which guide organizing efforts large and small. Firstly, disability justice recognizes the inherent value of all body-minds, the inseparable relationship

between mind and body, regardless of their perceived normalcy or output. It uplifts care work, maintenance, and creativity—labor performed by disabled people which is often unpaid and invisibilized—maintaining that "our worth is not dependent on what and how much we can produce" under capitalism [15]. Disability justice extends the disability culture term "crip time" [17], which demands sustainably-paced work in both personal life and movement building. By upholding the pace and labor of people with disabilities, disability justice also asks for organizing movements to be led by those most impacted by ableist conditions, where people with disabilities hold their own power to make change. These represent just several of disability justice's guiding principles, which have informed and inspired our work even as they remain in tension with traditional HCI research.

WHY WE NEED DISABILITY JUSTICE

When prompted with the question, "What does disability justice mean to you?" we heard diverse and wide-ranging perspectives from participants. One workshop participant responded that disability justice is to "take into account diverse needs of disabled or otherwise marginalized people in research, design processes or decision-making processes." Another responded, "learning and practicing being a good ally and working toward equity." Others saw it as a way of navigating the world as a disabled person. One participant said, "disability justice has helped me to understand and guide myself and my son through the experience of having a disability identity and navigating both internalized and external ableism." During the workshop, our breakout discussions explored topics such as accessible research methods, the impacts of AI/ML on disabled people, disability justice in the Global South, and the intersections of disability with race, gender, sexuality, and class.

These themes inevitably coalesced around a central question: Can disability justice even exist in the academy? Our position was dubious. After all, disability justice seeks to actively dismantle many of academia's most basic structures, from the hierarchical and peeping nature of participant research to capitalistic funding to the pace of publishing. One of our peers in the workshop, Frank Elavsky, put it best: "I don't see why disability justice would need HCI," they said, "but I can see how HCI would need disability justice" [18].

There is a strong sense that disability justice and academia cannot fit together, at least not without some pain. Indeed, there are huge tensions between infusing a disability justice praxis and ethos into academia. Our workshop began with discussions of how we could leverage our research skills and unique positions to support communities already practicing disability justice, as a matter of ethical research and cross-solidarity organizing. However, we soon realized that in order to support other communities, so many of us academics really needed disability justice for ourselves first.

We learned that despite these ableist structures, some researchers gravitate toward academia for the unique promise and potential of flexibility, which would be further out of reach in industry or non-profit spaces. Some talked about academia fitting their need for a flexible lifestyle, which made funding battles worth it. Few other industries, we remarked, could allow for entirely self-directed study and time management. Another peer mentioned that academia is among the only workplace in which they have the option to work on crip time, pacing themselves in a way that suits their bodymind. While overwork and a breakneck pace are professionally rewarded for graduate students, the academy nonetheless offers flexibility for our participants to take care of themselves. Grant-writing also represents a funding source for work that is deeply meaningful to individuals, work that may not otherwise get funded. For these reasons, many of our workshop participants remarked that, given just the right conditions, working in academia is actually helpful for supporting people with disabilities.

Yet, these promises of access often fall short. The same things that make academia inhospitable to a disability justice praxis – the pressure to move fast, enforced capitalist narratives, and working alongside and under those who don't value lived disability justice experiences – are also killing academics with access needs. Krys Méndez Ramírez writes for the Disability Visibility Project about the bureaucratic difficulties of getting recognized accommodations for multiple sclerosis [19]. Like many before them, Ramírez was hopeful that pursuing graduate work would allow them the flexibility to produce meaningful work while living with a disability. Instead, they report being met with obstacles from an institution that sees them only as "a liability, an implacable agitator, or just a threat to the academic status quo." Seeing the established culture of ableism, our workshop participants discussed that they stay and organize within academia because we need disability justice *everywhere*. Others have formed coalitions to make essential changes within publishing, from accessibility documentation within SIGCHI to guidelines on accessible talks within their own institutions. Though these practices do not represent disability justice in its entirety, the academic community uses disability justice to guide how we make change within our own institutions, with an orientation toward imagining liberatory futures.

HOW THE HCI COMMUNITY FAILS TO MEET DISABILITY JUSTICE PRINCIPLES

HCI has an interventionist drive that makes normative assumptions of intervention as urgent, necessary, and curative [20]. Whether we look to disability dongles or the eugenicist undertones underlying research [21], we see how this compulsion for "fixing" produces problematic results. But while HCI's laser beam is trained on fixing individuals, many academics *do not* yet practice intentional actions of resource redistribution or material aid or being involved in community-engaged work outside of academia. Lacking the capacity for material redistribution and real care work, we see how HCI's attempts at intervention instead amount to hegemony.

In light of our experiences within the academy, we draw out several mechanisms that explain why the ivory tower cannot engage with disability justice principles in its current form. We specifically look at the core of HCI to consider 1. what counts as valuable knowledge, 2. who conducts HCI research,

and 3) how we talk about HCI work. By examining these challenges, we join disability justice-informed critics such as Rua Mae Williams to encourage HCI researchers to instead take a more "nuanced, culturally informed, critical approach to disability in their work" [20].

What is "valued" knowledge in HCI? Since its origins as a field, HCI has been attempting to expand the boundaries of technically oriented research. But while design-oriented and humanistic approaches have become more accepted in the field, the HCI community continues to have a narrow definition of scholarship, which primarily focuses on technical advances for the sake of novelty and "progress" while failing to account for intersecting experiences across race, gender, disability, and socio-economic class. Our workshop participants continually expressed the sentiment that HCI is fixated on "trendy" technologies above research that critiques, reenvisions, or dismantles existing technical systems that reproduce/retain harmful social structures. This grain often ends up perpetuating epistemic harms against historically marginalized and disabled people, even (and especially) if the research centers on technically-focused accessibility [1]. For instance, HCI researchers who develop assistive technologies are seldom rewarded for expanding individuals' access to existing assistive devices or addressing low-tech accessibility needs across the wide variety of contexts in which they occur.

Part of the reason for this is the academy's obsession with generalizable knowledge. HCI often considers disability as a monolithic group; the level and severity of disability, interactions with others with their own disabilities, and interactions with other components of identity, as well as the corresponding methodological adjustments of the research are often ignored and unreported [22]. But the experience of a single disability is not generalizable. Not only does disability differ between each person, but also circumstantially and from day to day and year to year and context to context [23]. While untested technical advances provide the appearance of generalizability, creating on-the-ground access is often a tedious and individual process, depending on the unique circumstances of one's care.

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Disability justice emphasizes "leadership of the most impacted" precisely because those who deal with oppressive ableism have the deepest knowledge on how to undertake this process of change. disability justice, unlike academia, asks for particularized stories, seeing access as a continuous negotiation rather than a one-time fix. We see this in the writing and knowledge produced by disability justice activists, which tends to be highly personal and autobiographical even as it speaks to and with a larger community. Yet, because of systemic barriers, those who are *most* impacted cannot be found within elite academic institutions. HCI papers thus neglect works outside of the ivory tower; disability justice and disability-led scholarship end up being discounted, ignored, or misappropriated under HCI's narrow definition of scholarship [1]. The exception to this rule is for free labor, in which academics often ask people with disabilities to perform in academic spaces for "exposure" without expert compensation.

Finally, we note that HCI education teaches inaccessible methods that not only limit expert disabled perspectives from shaping the accessibility field, but also limit the participation of disabled people as participants in research and knowledge production. From recruitment to study participation, many bodyminds are left out of HCI research entirely. Traditional HCI methods (e.g., personas and simulations) taught in HCI education do not impart the knowledge of how to explore the holistic disabled experience, resulting in a shallow perception of disability among novice designers [24]. Individuals with

severe or multiple disabilities even get excluded from the recruitment process due to inconveniences, thus their voices remain unheard [25]. Many others choose to ignore the academy's quest for extractive knowledge, owing to past academic exploitation. By not teaching accessible research methods, HCI education ends up amplifying inaccessible forms of participation and limiting the kinds of perspectives available to our field. For example, inaccessible outcomes are perpetuated when out-of-date and ableist premises, like incomprehensibly formal consent language or gated compensation mechanisms, are taught to students.

Who conducts HCI research? Disability justice was founded in reaction to the white-dominated organizing from the disability rights movement to highlight the needs of intersectionally marginalized disabled people of color. Like the disability rights movement, the academy is also predominantly white with researchers largely inhabiting the global north. Unlike the disability rights movement, HCI researchers represent an elite and privileged class of academics who can publish in esteemed venues, and whose standards shape which perspectives matter.

This greatly impacts our peers from the Global South, who used time in the workshop to discuss how their scholarship is often devalued at HCI venues. While disability justice advocates for intersectionality, HCI research has largely ignored the specific challenges faced by disabled people in the Global South, where often communities grapple with unique socio-economic conditions and systemic barriers to accessibility that differ markedly from those of the global north. For instance, the emphasis on individual rights and autonomy, central to U.S.-based disability rights movements and prioritized in accessibility research via assistive devices that aim to replace human care, might clash with the communal and relational understandings of personhood prevalent in many societies of the Global South [26–27]. Here, we stress the importance of another disability justice principle, that of interdependence, which moves away from portraying disabled people as either dependent or independent, emphasizing that we are interdepen-

dent of each other [28]. In this context, the HCI research and practice engage deeply with local communities, scholars, and activists to co-develop contextually appropriate approaches to accessibility and inclusion. As a result, most content is not produced in English, and the international conferences in HCI are not the primary venue—the language and economic barriers prevent the majority from being part of the so-called international HCI community. Sustained engagement also means being careful of Western-led research that seeks to "parachute in" and then disappear once the funding ends or the paper is written. We envision a world where HCI researchers prioritize meaningful and sustainable changes to the material conditions of Global South communities, over research outputs that evaluate solutions that are removed from the community once the project is over, or, worse yet, never actually manifest in reality at all. These values underscore the importance of a decolonial approach to accessibility and HCI, one that decenters the global north, amplifies voices from the Global South, and understands disability justice as an approach that is both globally informed and locally relevant, ensuring that the movement toward access is genuinely inclusive of all global perspectives.

How do we talk about HCI work? Conferences are the heart of HCI and computing scholarship, where HCI research is discussed and disseminated. Because HCI literature is often inaccessible and behind paywalls, there exist few structures for the transference of benefits from academia to communities that research supposedly serves. Certainly, we already see some of this starting to change, albeit outside of a disability justice framework. In our workshop, we talked about a few individual steps to disrupt these tendencies, such as offering authorship to participants and writing plain language summaries of papers. However, much of this work is seen as an addition to or as a distraction from the "real" process of research.

Secondly, we find that conference spaces also exclude disabled scholars, scholars with visa constraints, and community members who are most impacted by accessibility work but

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lack institutional funding options. Here too, change is slow and shallow. For instance, the last few years have seen ACM-affiliated conferences revise their submission guidelines to require authors to provide alt text, image captions, and screen reader-accessible papers for review and publication. While technically more accessible, coordinating publication access puts additional strain on accessibility organizers while doing little to increase reviewer participation from people with disabilities. The COVID pandemic has also ushered in a new era of (slightly more affordable) remote attendance, which disabled scholars have long been advocating for. And yet, more needs to be done to make these meetings accessible, including taking remote and hybrid modalities seriously. While the ASSETS conference has at long last added a critical and inclusivity track to its programming, the separation of critical work means that traditional assistive technology scholars who are least familiar with such approaches remain siloed from them. Looking across these cases, we can simultaneously acknowledge the progress we see and invoke disability justice to push for access beyond a checklist approach. Disability activism and direct action have also inspired deeper, more critical changes in HCI conferences. Disabled scholars have protested the inaccessibility and inhospitality of HCI conferences: from the CHI 2019 crip sit-in [29] to "No CHI 2024 in Hawaii" efforts [30]. Spanning environmental justice and resistance to settler colonial harms, disability justice views various social

movements as interconnected in their pursuit of collective access under the leadership of the most impacted.

WHERE DO WE GO FROM HERE?
The goal of this article and our workshop is to unearth some of the complexities of disability justice and HCI research, interrogate our roles within these spaces, and extend an invitation to engage with disability justice as a guiding north star. This is best captured with one workshop participant's description of disability justice as *"messy, living, best-we-can-do-right-now communities and alliances that we make with other people who seek justice for all."*

But what does it mean to be in community with other people who seek justice? The common narrative in HCI is that one of the best ways for us to change the field is through more equitable forms of participation and collaboration. However, while it would be easy to suggest that HCI researchers should seek research partnerships with disabled people, we acknowledge that many individuals avoid academic collaborations to protect themselves and their communities for the reasons stated above. Before collaborating, we encourage researchers to do the work of imbuing disability justice principles into their own practices and their lives. Without this commitment, "collaboration" will only continue to result in harm and erasure of disabled communities. As we discuss the theoretical implications of valued knowledge and inclusion, we also want to be sensitive to the material, on-the-ground impacts our work produces. As Rua Williams points out "academics are rightfully criticized for co-opting Disability Justice as a mere theoretical contribution when engaging DJ as a means to enrich academic knowledge production rather than inspiring intentional actions of resource redistribution, material aid, and hegemonic sabotage" [31]. Following in the footsteps of author Akemi Nishida, we encourage HCI researchers to ask themselves, "What kind of relationship do I and my institution have with local disability communities and people? How does my work relate to their lives?" [32].

By doing this internal work, researchers can be powerful agents for

disrupting academic norms from the inside. For instance, we can commit to fair compensation practices and reject research projects that could be harmful or misaligned with community needs. When designing new (socio-)technical systems, we encourage researchers to consider whether they are solving real or contrived problems. Instead of making disability dongles, we can leverage our technical expertise to make assistive devices more affordable, more customizable for diverse bodyminds, or more repairable by individuals. A disability justice sensibility encourages us to push toward methodological innovation by questioning the premise of developments "for social good." These principles can be applied outside of accessibility research to benefit all of HCI. Attuning ourselves to the experiences and leadership of those most marginalized offers opportunities to use technologies as a means to audit and subvert harms, like detecting cases of ableist housing discrimination on social media [33].

To end, we do not claim to have "answers" or "solutions" to the various structural issues that make HCI incompatible with disability justice, nor do we think there is one linear path. Luckily, we can build and learn from HCI scholars already paving the way for introducing and drawing from disability justice in HCI, many of whom we cite throughout this article. We also call for citational justice that amplifies the works of disability justice activists, such as Mia Mingus, Alice Wong, and Leah Piepzna-Samarasinha. Despite the many challenges ahead, we still dream of a future where HCI fully embraces disability justice.

To learn more about our CHI 2022 "Dreaming Disability Justice in HCI" workshop, access additional resources about accessibility and disability justice, or join our Slack community, visit https://disabilityjusticeinhci.org/.

ACKNOWLEDGMENTS

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