

# Exploring Disability Culture Through Accounts of Disabled Innovators of Accessibility Technology

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## Abstract

Disability culture celebrates the diversity disability brings. Its consideration of the positive aspects of the disability experience (community, solidarity, creativity) offers a contrast to many other framings of disability. Disability culture thus has the potential to deepen understandings of accessibility and inform approaches to the design and research of accessibility technologies. To explore this potential, we begin by presenting a preliminary synthesis of disability culture for the accessibility research community, based on works of disability studies scholars and activists. We highlight cultural processes of finding community and building solidarity, valuing disabled agency and knowledge, and rejecting ableist norms. To see how these cultural aspects might inform accessibility technology design, we studied accessibility technologies made by disabled people for disabled people – interviewing disabled innovators who had created and disseminated accessibility technologies. We asked these innovators to share their stories and reflect on goals and values they imbued in their innovations. We analyzed how cultural themes of belonging, knowledge, and creativity influenced their work. Our work highlights the potential of a cultural lens in aligning accessibility technology with disabled people’s values as well as unearthing new directions for inquiry for the field.

## CCS Concepts

• Human-centered computing → Accessibility.

## Keywords

Innovators, Disability Culture

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## 1 Introduction

In a world where disability is often seen as a deficit or tragedy, disability culture offers a unique lens in how it “celebrate[s] a positive disabled identity and consciousness” [4]. Disability culture extends beyond traditional narratives of barriers faced by disabled people to also recognize disabled people’s many acts of resistance, creativity,

and connection in everyday life. Encompassing a broad range of disabled experiences – from disabled people’s historical oppression to their present day ingenuity and future imaginings – it has the potential to illuminate new opportunities for accessibility technology design and research.

While disability culture has been discussed in activist and creative spaces (e.g., [1, 44, 67]), it has not received much attention in accessibility research. Just as the social model of disability guided us to explore access through structural changes rather than individual adaptations [37], and just as a grounding in interdependence guided us to explore social or collective approaches to access [5], disability culture too can deeply inform our work on accessibility. Particularly, we believe it has the power to help us move beyond “problem solving” in accessibility research [25] and recognize that access is not just about addressing barriers but also “a way of being together and helping one another” [5]. We draw inspiration from Spiel *et al*’s work exploring how we can ground our participatory feedback methods in disability culture [57] to more broadly explore how disability culture can inform accessibility technology design.

To understand how disability culture impacts access technology design, we must find examples of access technology that are grounded in disabled experiences and values, and unencumbered by ableist / ablebodied biases. Technologies designed by medical professionals, for example, are typically grounded in medical understandings of disability as individual impairment. Instead, we turn to access technologies designed by disabled people, for disabled people. We were motivated by the historical examples of Louis Braille and Robert Weitbrecht to seek out present day disabled innovators of accessibility technology. While disabled people’s practices of designing customized technologies for themselves could also offer insights, we were hoping to investigate this cultural phenomena at a larger scale – so we conducted an interview study with innovators whose accessibility innovations were disseminated and used in the community. Along with hoping to highlighting these disabled innovators contributions to access, we also examined what values these innovators infused into their innovations, and what that their design process and outcomes could teach us about disability culture. We use these examples to explore how grounding accessibility research in a cultural understanding of disability might help us imagine new kinds of accessibility technology.

First, in Section 3, we explore what disability culture means, drawing on works of disability studies scholars and activists as well as other accounts made by people with disabilities. Our synthesis highlights different facets of disability culture by examining how themes of identity, knowledge, and creativity surface in these works. In Section 4, we present mini biographies of disabled innovators we interviewed, highlighting their experiences creating and



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disseminating their work. Then through our analysis in Section 5, we examine how facets of disability culture and themes of identity, knowledge, and creativity surface in their work.

We find that rather than *just* addressing disability-related barriers in the moment, disabled innovators’ accessibility technologies work to build solidarity amongst disabled people, champion crip knowledges, and dismantle ableist norms. Their innovations are not simply infused with cultural values but also actively facilitate cultural processes of finding community, sharing knowledge, and discovering new ways of being. Their stories highlight how disability culture leans into “*transformative power of disability*” [43], and inspire us to do the same – reimagining goals and approaches to accessibility technology.

## 2 Background

How we understand and conceptualize disability has shaped how we approach the work of access. In 2010, Mankoff *et al.* [37] highlighted how most accessibility technology research has implicitly followed a medical conceptualization of disability, and thus has led researchers to prioritize approaches that minimize individual differences or ‘fix’ disabled people. Since then, there has been a shift in accessibility technology (AT) research, with many researchers drawing on other models of disability and exploring new orientations to access (e.g., [5, 66]). For example, Bennett *et al.* [5] questioned the traditional focus on ‘promoting independence’ in AT design and research, highlighting the fundamental interdependence of all communities. They proposed interdependence as a new frame for accessibility research – centering collaborative access and recognizing the role disabled people play in fostering access.

There is still a need to cultivate different understandings of disability and access. Recent discourses have drawn attention to the interventionist nature of accessibility technology research [65], highlighting that the implicit focus on eliminating disability embeds ableist biases in technology [54]. For example, consider popular media and science fiction representations of disabled people with prostheses as cyborgs – they are often depicted as superhuman and technology is only ever “*a source only of new powers, never of problems*” [55]. In reality, disabled people’s relationship to their technology is complex: sometimes contentious, sometimes empowering [48]. We need to think critically about the role of technology and discourses we weave around it.

Our focus on practices of disabled-led innovation in this work is inspired by Hamraie *et al.*’s Crip Technoscience manifesto [21]. They highlight disabled people’s many engagements in reshaping the world (scholarship, activism, and design) while still “*committing to disability as a difference that matters*” [21]. Their practices offer a valuable way to reimagine disability-technology relations. While disabled design and hacking has received much scholarship (e.g., [20, 23]), in accessibility research, most focus has been on the phenomenon of do-it-yourself accessibility technology (DIY-AT). Motivated by advances in technology and the potential to design high-quality, customized solutions to an individual’s needs, this body of work studies current DIY-AT practices (e.g., [24, 49]) and explores how to better support them (e.g., [26]). However, researchers have found that it is often the stakeholders around a person with disability that end up leveraging DIY-AT mechanisms, making it

“for” people with disabilities rather than “with” or “by” them [41]. There is also a need to highlight disabled people’s contributions to access [6].

Our focus on disability culture in this work is similarly guided by the need position disability “*as political, as valuable, as integral*” [30]. In addition to valuing a future with disability, disability culture also offers a unique way to pay attention to connections important to disabled people and the situated knowledges they hold – both of which have also been lacking in accessibility research [25, 57]. Motivated by calls to attend to the “*sociocultural fabric of disabled communities*” [3] and center the “*history and context of disabled people*” [25] in accessibility research, we take a disability culture lens on our exploration of disabled innovators of accessibility technologies.

## 3 What is Disability Culture?

The movement toward a disability cultural identity is increasingly visible in the disability justice movement, Deaf history, and related contexts. In this section, we begin by recounting how disability, culture, and technology are entwined before diving history of concept and understandings of the term.

### 3.1 Disability, Culture, and Technology

Increasing attention is being drawn to the relationship between culture and technology – technology is both reshaping and being shaped by culture. Biases embedded in technologies can perpetuate harm against those from marginalized communities and cultures. While mitigating these biases and harms is a promising avenue of work, researchers have also been exploring how we might instead design technology to imbue and foster values held by these communities and cultures (e.g., [31, 61]). Not only does this approach diversify built technologies, it also amplifies the creativity, resilience, power, and agency of these communities. How these cultural approaches might apply to accessibility research or disability culture is an open avenue of inquiry.

One way technology has reshaped disability culture is through the creation of digital spaces. These spaces allow people with disabilities who have otherwise been isolated from each other to connect, share their stories, and disseminate information. They have also offered disabled people a way to counter ableist narratives of disability in popular discourse (which often depict disability as ‘other’ or as a deficit or tragedy) [52] with their own lived experiences and imaginings of the future – their own *cultural expressions* (e.g., performance by disability justice collective Sins Invalid<sup>1</sup> and many more examples highlighted in [13]). Both the connections fostered as well as the stories told in these digital spaces have strengthened disability activism efforts – for example, the Disability Visibility Project<sup>2</sup> [67] builds online spaces for disabled people to share their lived experiences, supports and amplifies the work of other disabled individuals and organizations, collaborates with activists in campaigns (e.g., #CriptheVote) – thus champions disability culture and history.

One way culture has better informed accessibility research is in the context of DHH technologies. Deaf communities have long

<sup>1</sup><https://sinsinvalid.org/>

<sup>2</sup><https://disabilityvisibilityproject.com/>

since advocated for the recognition of Deaf culture (and “Deafhood” [33]) shared by those who share a common signed language [46]. Through this lens, deafness is not a deficit, but rather contributes to the diversity of the world. Accessibility technology that ignores this cultural perspective has sparked significant critique and activism (e.g., sign language gloves [17] or even cochlear implants marketed to hearing parents) – for not matching the needs of the community, for reinforcing hearing ways of being, and for disrespecting sign language [16, 22, 32]. A culturally informed approach instead advocates centering Deaf values (e.g., respecting sign languages and Deaf expertise, considering communication as a collaborative endeavor) – an approach that many accessibility researchers are orienting to (e.g., [2, 7, 8, 39, 62]).

### 3.2 Tracing ‘Disability Culture’

The concept of ‘disability culture’ arose in late 1980s. Steve Brown (then disability activist and historian, now considered the father of disability culture) explored the concept through conversations with other people with disabilities, asking them to share their stories [58]. He found that most people had very passionate reactions to the idea of ‘disability culture’ – both for and against it. Those who were opposed to it mainly felt that disability had such a negative connotation to it, that something positive like ‘disability culture’ couldn’t exist. In fact, Shakespeare’s paper on the social model [53] states that *‘disability pride is problematic’* as disability refers to either oppression or impairment, which are both negative. It is these very reasons that show why disability culture as a concept is important. As put by Brenda Brueggemann [13] in her work tracing disability culture, disability culture is central to approaching disability/lives of disabled people through a ‘positive psych’ or non-pathological lens. In his oral history, Steve Brown remarked on why he felt disability pride was so important: *“People with disabilities are not going to be integrated into society the way we would like to be as long as we’re trying to be non-disabled [...] because we want to be integrated as we are and in order to do that I think we have to have pride in who we are”* [59]. Disability culture looks beyond inclusion to recognize the fundamental value of disabled lives – highlighting disabled joy and creativity and celebrating the diversity disability brings. It has been gaining increasing traction over the years, and is bolstered by the rise of cultural centers for people with disabilities in many cities.

Because of the many different experiences of disability and the many different meanings of culture, there are many nuances in people’s understanding of the term ‘disability culture’ and their expressions of the concept [11]. Defining culture alone has generated significant debate and scholarship – people consider various combinations of beliefs, attitudes, customs, heritage, music, art, literature and more [64]. Rather than attempting to synthesize an encompassing definition of disability culture in this work, we explored how key cultural themes of sense negotiating identity, sharing beliefs and knowledge, and discovering new ways of being occur in the context of disability culture. We draw from disability studies literature as well as various accounts by disabled people to inform our synthesis.

**3.2.1 Finding Community and Building Solidarity (Claiming Crip).** A sense of community and belonging is central to many cultures.

But unlike many regional cultures, disabled people aren’t always born to families with disabilities. Many disabled people have remarked on how important it was to find community and others who share the experience of disability: *“disability culture allows us to see our identities not as a weird set of coincidences but as a kinship”* [29]. Coming together helps recognize how it is not individual flaws, but systemic ableism that has been used to oppress all disabled people. Simi Linton famously said, *“[W]e are bound together, not by [a] list of our collective symptoms but by the social and political circumstances that have forged us as a group”* [35]. Mia Mingus how this understanding fostered her identity as *politically disabled* – *“someone who has an analysis about ableism, power, privilege, who feels connected to and is in solidarity with other disabled people [...] someone who thinks of disability as a political identity/experience, grounded in their descriptive lived experience”* [42].

Finding community not only facilitates a different understanding of disability, but also nurtures collective imagining of different futures. Disability has so long been seen as a tragedy that the future of anyone with a disability is considered bleak. But Alison Kafer shared the power of connection: *“[disabled people] tell stories of lives lived fully, my future according to them, involves not isolation and pathos but community and possibility.”* [30].

Negotiating a sense of belonging in disability culture is an ongoing process, and is often complicated by shifting abilities. Neil Marcus shared in his poem *“If there was a country called disabled / I would be from there / ... / In my life’s journey / I am making myself / At home in my country”* [12, 45]. Many have discussed this journey and called it ‘claiming crip’ (e.g., [50]) – a phrase that tips its hat to the history of the word crip and its reclamation by the disability community [27]. This negotiation of identity is not only shaped by one own feelings but also by how bounds of disability change over time (e.g., to include or exclude certain diagnoses or experiences).

**3.2.2 Valuing Agency and Disabled Knowledge (Cripepistemologies).** Culture shapes our what we believe, the kinds of experiences we value, and how we seek and share knowledge.

A key part of disability culture is questioning dominant perspectives of who has knowledge about disability. The history of institutionalization shows that beyond being framed as undesirable, power has been taken away from disabled people and their experiences and knowledge are discredited or dismissed. Key themes of the disability rights movement were fighting for power, agency, autonomy – *“nothing about us without us”* [13]. Along with agency to be part of decisions that impact their lives, disabled people have also fought to be recognized as experts in their own experiences.

Additionally, disability culture recognizes that disability *itself* is a valuable way of knowing about the world. Many disabled people have shared how they *“see the world and [their] relationships in it through a different lens”* [19]. They have acquired a deep and different knowledge of society from their experiences navigating a world – a kind of ‘embodied’ knowledge [56]. Many therefore see *“disability as an ingenious way to live”* [12]. Disabled people also often share this knowledge, gained from lived experience, with others who need it – thus taking disability from an individual experience of *“perceiving and orienting to the world”* [60] to a collective *“body of knowledge”* [56]. This reframing of disability as generative is rooted in the historical context: *“We need to celebrate [what disability has*

to offer] because no one should have power of deciding about us or over us, no one should decide about the value of our lives” [15].

**3.2.3 Recognizing/Rejecting and Flipping Norms (Crippling).** For many cultures, scholars have considered two different senses of culture: the common everyday aspects (“a whole way of life”) and the processes of discovery and creativity (“the arts and learning”) [64]. For disability culture, these two senses are deeply entwined because navigating everyday life demands creativity, especially in a world made of structures that are inaccessible and ableist. This is a result of a society that overvalues normalcy and uses norms to other, oppress, and exclude disabled people. Many disabled people have recognized if disability is to be a part of the future, we need to transform the world.

Disabled scholars, activists and communities have taken a layered approach to this. One part is changing the stories told about disability and bringing to question the undesirability of disability. As put by Kafer, “How one understands disability in the present determines how one imagines disability in the future; one’s assumptions about the experience of disability create one’s conception of a better future.” [30]. Deeper understanding of disabled people’s experiences – both the joy and frustrations – can help check the assumption that the only desirable future for disability is in which it is eliminated. At the same time, unfurling these joys and frustrations, disabled people explore what a better future looks like: A future in which we value disabled knowledge and creativity and diversity but also condemn the violence that causes illness and impairment, where we question the ideological systems that frame some as normal and others as deviant, where we dismantle structures that continue to exclude different bodies and minds.

Crippling then is practices or actions disabled people take in realization of this better future – disrupting the status quo and flipping norms [40]. Crippling often refers to ways disabled people hack their environments and technologies, but is not limited to material changes – it can also be social or ideological or infrastructural reform [21]. There is no singular way to ‘crip’ – it can be through raising awareness, sharing stories, creating art, protesting, adapting spaces, hacking technologies – all are transformative.

### 3.3 Summary and Connections

The three facets we have described here are not mutually exclusive nor comprehensive. Our goal in looking at disability culture through these different themes is to help recognize the multiple ways we can orient to or engage with culture in our work. We also hope that articulating these different strands makes it easier to see how they entwine with each other and how we might weave them together in new ways. We need community to share knowledge and stories with, together we can imagine and create different futures and ‘tap into the transformative power of disability’ (Mingus) [43].

Our discussion of these cultural themes is also situated in a particular space and time – a time where technology is increasingly shaping and being shaped by disability culture. Not only is technology facilitating disabled connection and organization, disabled people’s stories and activism are also transforming digital spaces. Recognizing disabled people as not only users of technology but also creators and hackers in their own right then makes clear the potential for us to learn about disability culture from what they

build. Steve Brown emphasized that disabled people infuse their creations with their lived experiences and culture, so what values do disabled people imbue in the technologies they build?

## 4 Gathering Accounts of Disabled Innovators

In this section, we first begin by discussing historical disabled innovators that prompted our exploration of this space. We then discuss our data collection and analysis methods for our study of present-day disabled innovators of accessibility technologies. We introduce these innovators through short vignettes.

### 4.1 Motivating Innovators

Our study of disabled innovators was driven, in part, by recognizing their contributions to accessible technology from the past. For example, consider Louis Braille, known for his development of Braille: a system of raised dots that represent letters of the alphabet and other written symbols [28]. While other approaches to making reading accessible existed at the time, writing was largely inaccessible to blind individuals. Braille offered an alternative: a tactile writing system accessible to blind people. Another example is Robert Weitbrecht, known for his contributions to the teletypewriter (TTY [34]). At that time, telephones made it possible for hearing people to communicate with each other remotely and quickly, but such remote communication options were limited for the d/Deaf and hard of hearing people. While radio TTys allowed communication with morse code, their range was limited to small ham radio communities. Weitbrecht developed an acoustic coupler that worked with standard phone lines, expanding the range of TTys.

Both Braille and the TTY have had a tremendous impact on many disabled lives. Louis Braille and Weitbrecht were motivated by their own needs but also by a desire for more connection amongst disabled people. Their innovations would have only had impact through shared and widespread adoption, and the inventions were realized through collaboration with both disabled and non-disabled people. They combined their skill set and lived experience with others. Their innovation’s success was also a result of large-scale change and advocacy spearheaded by disabled people and their allies (e.g., blind students and teachers advocated for Braille to be adopted in schools, organizations like NAD<sup>3</sup> and TDI<sup>4</sup> helped mandate infrastructural support for TTys). Motivated by this history, and curious about similarities and differences, we interviewed present day disabled innovators of accessibility technology.

### 4.2 Data Collection and Analysis

Our aim was to gather and understand the design activities of disabled innovators of accessibility technologies. Our focus on innovators meant we searched for those who not only created something to meet their access needs, but also worked to disseminate it. We considered any accessibility technologies that increased disabled people’s access to physical and digital spaces, such as technologies to support mobility and sensory access needs (e.g., wheelchairs, screenreaders, hearing aids) as well as any technologies that promoted access figuratively i.e., increases opportunities for social and political participation.

<sup>3</sup>National Association for the Deaf

<sup>4</sup>Telecommunication for the Deaf Incorporated

Through searches of public record as well as personal knowledge, we compiled an initial list of innovators. We took two approaches: first, listed innovators we knew from our community and professional networks as well as other public figures. One author has worked in this space of accessibility for decades and thus knew of many potential candidates. Second, we conducted a web-search using terms like “disabled innovators”, “innovators with disabilities”, “inventions by people with disabilities” and similar variations to find any other pre-existing lists (e.g., Think and Zoom’s annual global list of disabled innovators) and reviewed them for specifically innovators of accessibility technologies. To further assess eligibility of candidates, we reviewed any associated web media (websites, articles, blog posts, YouTube videos, TedTalks). We contacted these innovators for interviews, and if they expressed interest in speaking with us, we conducted a semi-structured interview over video conferencing software of choice or asynchronously. We may have missed innovators who have not disclosed their disability publicly, as well as those whose role in innovating has not been documented well. Data collection took place in 2020-2021.

In the interviews, we took a phenomenological approach [51] and structured our discussion in three-parts focused life history (disability and accessibility experiences), details of the phenomenon (building accessibility technology), experience in context (how life and learning experiences informed design choices). This allowed for a contextualized dive into participants’ perspectives as innovators and disabled people, as makers and users of assistive tech. We then analyzed these interviews using reflexive thematic analysis [9, 10].

### 4.3 Participant Vignettes

Below are vignettes of our participants and their innovations. Many of our participants emphasized they did not work solo, often collaborating with other people with disabilities and as a part of a team. We spoke to them as leaders in their teams and in the innovation process. The first five innovators were interviewed synchronously, and the others were interviewed asynchronously. All participants gave permission to share their names and stories.

Innovator Name	Innovation(s)
Greg Scott	SoundPrint
Ed Summers	SAS Graphics Accelerator
Rory Cooper	MEBot (among others)
Melissa Greenlee	Deaffriendly
Michael Curran	NVDA
TV Raman*	Emacspeak
Brendan Gramer*	CaptionFish

**Table 1: Innovators in our study and their innovations at a glance. Asterisk represents asynchronous interviewees.**

**4.3.1 Greg Scott.** As a person with hearing loss, Greg would often try to find quiet places for meeting people and socializing. But information about noise level was hard to find using typical search platforms and was often inaccurate. Greg also couldn’t rely on his own judgment of the noise level since hearing aids are notoriously hard to calibrate in such environments. So he started carrying decibel meters around to restaurants and began marking their noise levels. Over time, he curated his own list of quiet restaurants around New York, making finding a socializing spot easy. But whenever

he traveled to a new place, he once again couldn’t easily find quiet places: “*finding quieter venues is really difficult in a world that continues to get noisier.*” (Greg). This motivated him to create SoundPrint.

SoundPrint<sup>5</sup> is an app that allows users to measure and share the noise levels of different venues such as restaurants, bars and cafes. These crowdsourced measurements allow users to easily access noise information of an unfamiliar place. It also helps user discover quiet places in a city through community-sourced lists. Since “*noise-inducing loss is a public health issue*” (Greg), Greg also wanted to offer a way to help people protect their hearing health. SoundPrint therefore also notifies users if they are in an environment that is harmful to their hearing. Users then have the option to file a noise complaint with the app, which would prompt SoundPrint to reach out to the venue about how noise exposure could be harmful to both employees and patrons. They offer inexpensive tips to mitigate noise, express benefits of having an accessible venue from an acoustic perspective, and offer expertise in the form of acoustic suppliers or consultants.

**4.3.2 Ed Summers.** When we spoke with Ed, he was the accessibility chair at SAS, a company that offers a platform and software for data management, analysis, and modeling. Prior to becoming accessibility chair, he had been a long-time employee at SAS – and as a computer scientist who rapidly went blind, he had spent years thinking and navigating about non-visual access to data. When he became lead of the program, he found himself in a position where he could work help expand the agenda from fixing existing accessibility bugs in the software to exploring new paradigms for non-visual access to data visualization. This then motivated the creation of the SAS Graphics Accelerator.

The SAS Graphics Accelerator<sup>6</sup> is a software that provides accessible and alternative presentations of data visualizations. It includes enhanced visual rendering, text descriptions, and interactive sonification (which uses non-speech audio to convey information about graphs), thus enabling BLV individuals to create and explore data visualizations. The development process was informed by Ed’s own experiences as well as those of his team of blind engineers, helping them gain “*a deep understanding of how competent blind users use their assistive technology*” (Ed). They iteratively explored how they might map information embedded in graphs to audio while maintaining understandability. They were also committed to designing in a way that would scale-up and integrate with new and existing SAS technology.

**4.3.3 Rory Cooper.** While serving in the army, Rory sustained a spinal cord injury. He had always been drawn to science and took the opportunity to pursue an engineering degree through the GI Bill. This was before the Americans with Disability Act was passed, and so he had to work with his professors and peers on navigating access barriers. He ended up working on engineering projects based on his own needs, like a standing electric-powered wheelchair to reach higher, immovable pieces of equipment in labs. Rory described how this happened frequently through his degree, “*I was a runner before I was injured. And I wanted to go back to running. So I started building racing wheelchairs. Then the triathlon started.*”

<sup>5</sup><https://www.soundprint.co/>

<sup>6</sup><https://support.sas.com/software/products/graphics-accelerator/index.html>

*And I wanted to do a triathlon. So I built the hand cycle.[... and then I] started building [lighter weight] everyday wheelchairs” (Rory). Rory eventually pursued a doctoral degree and is now the director of Human Engineering Research Laboratories (HERL).*

HERL<sup>7</sup> is “a one-of-a-kind setting for developing solutions for people with disabilities by people with disabilities”. They work on improving mobility and function by conducting studies as well as developing products to support their access needs. Since the inception of the lab, Rory has worked on many innovations that have been patented and disseminated, including the MEBot (robotic wheelchair that self-levels and climbs curbs), the variable compliance joystick (which is used in every power wheelchair and supports independent mobility), the smart wheel for wheelchairs (measures forces and moments on pushrims), among many others. Rory remarked on HERL being unique in not only the involvement of disabled in the development process, but also in “*how everything that we’ve invented is on the market, in some form*” (Rory).

**4.3.4 Melissa Greenlee.** Melissa started gradually losing her hearing during her childhood and was struck by the stark differences in navigating the world as a Deaf person vs. a hearing person. In running errands and interacting with different businesses as consumer, she found herself deeply frustrated by the “deer in headlights” look from people when they realized she couldn’t hear. While traditional review platforms like Yelp offered a space to complain and offer feedback to businesses, she realized these platforms were not designed to write about what she cared about as a Deaf person – “[*I wanted to change*] how the consumer experience was happening for me and for my community.” (Melissa). This motivated her to create DeafFriendly.

DeafFriendly<sup>8</sup> a consumer review platform that allows d/Deaf and hard-of-hearing (d/DHH) people to review different businesses on the accessibility of their experience. DeafFriendly thus helps d/DHH individuals find accessible places. Additionally, Melissa recognized that “*businesses really do pay attention to their reviews online*” (Melissa) – so as a public platform, it encourages businesses to engage with these reviews. Since many business “*just don’t know how*” (Melissa) to communicate accessibly, they also educate businesses and provide trainings.

**4.3.5 Michael Curran.** When Michael was around 15 years old, he lost his remaining sight and ended up receiving a laptop with JAWS screenreader from a local charity. This sparked his interest in computers and programming, which he pursued in school. He and his friend Jamie were frustrated about the cost of commercial screenreaders and the lack of free alternatives – “*We believed that wasn’t right, that a blind person shouldn’t have to pay more than a sighted person to use a computer*” (Michael). Combining his interest in coding with his passion for blindness advocacy, he started working on NVDA.

NVDA<sup>9</sup> is an open-source screen reader software for Windows. It began with Michael “*cobbling together a few Python libraries to make a basic screenreader*” (Michael) and has now grown into a modular, standards-based screenreader that is highly efficient and performant. As open-source software, it allows contributions from

software developers everywhere, and keeps developing iteratively. It is used worldwide by thousands of people and has been translated to several different languages. Additionally, NV Access, an Australian-based charity, helps keeps NVDA free and offers accessibility consulting to companies to make their technologies work well with NVDA.

**4.3.6 TV Raman.** While pursuing his PhD, TV Raman took an algorithms class that involved materials in LaTeX. When he tried to read them with his screenreader he “*quickly realized how unusable that was*” (TV). This motivated his dissertation work on AsTeR, a computing system for rendering technical documents in audio. This work then led to Emacspeak a few years later.

Emacspeak<sup>10</sup> is a speech interface and audio desktop that enables blind and visually impaired individuals to interact efficiently with the computer. It began with TV’s desire to work with a Linux laptop and develop something that “*treats speech as a first-class interaction modality with respect to how things are spoken and make information access via the keyboard as efficient as possible*” (TV). He built it for himself and iterated rapidly, before releasing it online. With the development of the web over the years, it has been continuously updated to support new functionalities e.g., access to media streams, instant messaging, blogging, and leverage web APIs [63].

**4.3.7 Brendan Gramer.** Brendan wanted to find out where captioned movies were playing nearby easily and thus designed CaptionFish, a website and iOS app, along with two other Deaf collaborators. CaptionFish helped users find theaters that were showing captioned films and offered an internet listing of current and upcoming movies with the detailed information about the type of captions available (open captioned, closed captioned, subtitled etc.) He hoped that in addition to keeping the d/Deaf community better informed, it would “*create more opportunities for the d/Deaf community to positively advocate for equal access*” (Brendan) by showing the community had “*purchasing power*” (Brendan) and theaters should offer more captions. CaptionFish has since been sold<sup>11</sup>.

## 5 Taking a Cultural Lens on Disabled Innovators’ Designs and Processes

We begin by contrasting our participants’ stories to our historical innovators. Similar to innovators from the past, our participants’ innovations were often motivated by personal experiences and needs they saw day-to-day. They also worked collaboratively to bring their ideas to life – combining their lived experience and skill set (be it technical or business related or leadership) with others’ expertise.

Compared to past innovators, our present innovators experienced a significant change in the technological landscape– the proliferation of high tech rapid prototyping tools (flexible manufacturing tools, computer-aided design software), the development new digital realms to mediate access in (e.g., access to websites, data viz), and the conceptualization of crowdsourcing infrastructure. These technological advancements shaped their innovation

<sup>7</sup><https://www.herl.pitt.edu/>

<sup>8</sup><https://www.deaffriendly.com/>

<sup>9</sup><https://www.nvaccess.org/>

<sup>10</sup><https://emacspeak.sourceforge.net/>

<sup>11</sup><https://www.captionfish.com/> (Retired Website)

approaches (e.g., leveraging multiple contributors, designing customized AT) and innovation constraints (supporting dynamic access with changing data and screens).

While there has also been a change in social and legal climate around disabilities (e.g., passage of the ADA), our innovators also faced barriers in access to education, accommodation, and resources along with typical challenges while innovating: “[Law] provides a framework. It doesn’t change culture and people.” (Rory). Beyond sparking the initial idea, innovators’ design and collaboration processes were also fundamentally shaped by questions of access. For example, Melissa shared, “There’s so much free content online about how to write a business plan [...] and none of it was accessible with captions or interpreters.” (Melissa). Many innovators shared experiences of working around such barriers and teaching themselves what they needed to know.

These barriers were frustrating for participants: “Companies [are] not making things accessible when they could” (Michael). This experience is common to many people with disabilities, but impacted our participants at a personal and professional level, “I’m reminded about it a lot more because we’re interacting with these products and companies every day.” (Michael). Yet, despite and perhaps because of these frustrations, our innovators were steadfast in their goals to create something that would support their own needs and the needs of others like them. They were guided by their lived experiences and worked to imbue their innovations with their values. In the following sections, we begin by exploring how cultural themes of crip identity, crip knowledge, and crippling the world come up in these disabled innovators processes. We then examine how they balanced different trade-offs in their journey and how they felt empowered through the process.

## 5.1 Accessibility Technology Building Solidarity (Claiming Crip)

Themes of community were prevalent in our participants’ stories. For example, Melissa shared how meeting other Deaf people and being exposed to Deaf culture as an adult kicked into gear the process of claiming a Deaf identity: “A long process of, you know, kind of opening up and then shutting down [...] It’s been a very positive thing to interact and engage with other people [like me]. Before I just very alone.” (Melissa). Both the lived experience of disability and finding community acted as a catalyst for starting DeafFriendly.

For other innovators, community came up in different ways. They expressed the deep joy of collaborating with other people with disabilities on their innovation and the certainty “the whole was greater than the sum of the parts” (Ed). Much of what they loved about the process revolved around the ways they could lean on each others’ professional and personal expertise to come up with creative and robust solutions—reminiscent of the power of the collective imagination. Rory described how he had built a network over the years of disabled people with varied experiences and expertise, and found over the years he designed less technology for himself, and “more for other people. [...] less *for* but more *with* other people.” (Rory).

Interestingly, we see that for some innovators, community was fostered actually as a result of their innovation. For example, Michael discussed the open-source nature of NVDA and the hundreds of

contributions from BLV programmers worldwide, “There have been many contributions to the project. And it’s really great to see that it’s not really just a software project, but it’s actually, in some ways, it’s a movement. It’s a community. [...] NVDA is by users, for users.” (Michael). Greg also expressed a similar sentiment about SoundPrint: “Even though I designed it for those with hearing loss and vision loss, there are a lot of people who don’t have any disabilities who use the app. [...] It’s really a community of people that care about noise, who actually feel underrepresented [...] I take a lot of pride in building that community on top of the personal mission to help people like me who had a similar need.” (Greg).

Along with helping disabled people connect with others like them and not feel alone, NVDA and SoundPrint also created a mechanism for people to contribute to accessibility: allowing them to come together in their mission to make the world more accessible. In this way, we can see that accessibility technologies also negotiate the process of claiming identity, going in Mingus’ terms from ‘descriptively disabled’ to ‘politically disabled’ – to be in solidarity with other people with disabilities, recognize ableism underscoring our structures, and contribute to access.

## 5.2 Accessibility Technology Championing Disabled Knowledge (Cripepistemologies)

Innovators’ lived experiences and the corresponding crip knowledge shaped both the high-level idea behind their innovations and the smallest of design choices. For example, consider the way SAS Graphics Accelerator carefully avoids interference between sonification and the screenreader audio using a timing mechanism. The innovators shared how they thought these “little things” (Ed) were what helped make their innovation successful, and were grounded in intricate knowledge disabled people acquire from repeatedly using these access technologies: “If you don’t use a wheelchair, you’re just never going to get the same amount of experience that I do. [...] The fact is that you can notice very subtle differences, just because you just use it all the time.” (Rory).

These ‘subtle differences’ went beyond just their experiences with accessibility technologies to their interactions with the world. Melissa spoke to this at depth, sharing her experiences navigating everyday life as a young hearing person vs. as a Deaf person, noting how differently “the world responds to the two different kinds of people” (Melissa). She found that most lacked awareness on how to communicate without centering speech and spoken norms, but that was something she naturally brought to the table with her as a Deaf person. She therefore works on sharing this knowledge through DeafFriendly and showing businesses different ways to communicate and make their services accessible.

Innovators also shared how their disability made them perceive the world in a different way, and thus embody a different knowledge of society. Greg’s experience with calibrating hearing aids and his need for quiet environments made him perceive each restaurant or cafe through this lens—allowing him to curate a list of quiet spaces over time. This list was a resource that many of his friends and family came to value and was only born out of Greg recognizing the unique knowledge of society he embodied. Similarly, Melissa realized her early Yelp reviews focused on different things as a Deaf



person – *“the waitress wouldn’t write things down or, the environment was very noisy, I couldn’t even speechread [with the lighting]”* (Melissa). This recognition of the value of knowledge they acquired with each interaction with the world and the recognition that every disabled person similarly embodied knowledge of society prompted them to design technologies that crowdsourced information about the world, collectively pooling together resources and creating *repositories of crip knowledge* that could then be shared with other disabled people.

Cherishing crip knowledge was a value shared by many other innovators and was further nuanced by the diversity of disabled realities. Ed spoke of working with a team of blind engineers, each having very different experiences with blindness, from when and how they had acquired it to how they navigated it. These different experiences led to different opinions on their design choices and speculations while innovating: *“Oh, it’s wonderful [...] I think our design process is much richer, much more robust [...] because we have] different opinions, different perspectives. [...] Sometimes that] surfaces in a way that is explicit and sometimes I think it’s implicit. [...] It’s good. It creates that creative tension.”* (Ed). While collaborating with other disabled people offers that richness and robustness, Rory found that in his experience working with disabled scientists, engineers, and clinicians the expertise they brought was *“not only from a personal perspective and professional perspective, but also from the social perspective, by interacting with other people with disabilities.”* (Rory). They held knowledge not only of the diversity of lived experiences, but also amplified it when they could, guided by a deep appreciation of the innovative power of diversity in shaping design processes and research agendas.

We also found that innovators actively sought this diversity in their innovation process – through the contractors they hired (Melissa), the teams they brought together (Rory), or how they the set up contributions to their projects (Michael). For the latter, consider NVDA’s commitment to being open-source. Michael shared that all screenreaders before NVDA were commercial and closed-source, preventing anyone from improving upon them without having to first *“reinvent the wheel”* (Michael). He was excited that NVDA’s code was out there for future developers: *“They can use NVDA as a reference when they move forward, and improve upon it.”* (Michael). He shared how this has already begun happening with the large number of BLV contributors updating NVDA based on their needs and experiences. For example, contributors from Brazil and Slovakia wanted to translate NVDA, so they *“made sure that there were the facilities in the NVDA development life cycle”* (Michael) to support that.

Overall, we see that these innovators clearly recognized unique crip knowledge they and other disabled collaborators hold – they creatively used this embodied knowledge to inform their innovations’ designs and shape their collaboration processes, forming new mechanisms to document and share crip knowledge.

### 5.3 Accessibility Technology Dismantling Norms (Crippling)

Our innovators were intimately familiar with the ableism and inaccessibility of society, and were driven to impact real-world change through their work. For Ed, that meant a guiding value when they

started working on the SAS Graphics Accelerator was to make sure *“it’s not just locked up in an academic kind of style research experiment, but it actually is integrated with a widely used product.”* (Ed). For Rory, it also impacted at what stage they shared their innovations and how they iterated on them. Describing his approach, he said, *“Don’t let perfect be the enemy of good... we should get it out there. We can continue to work on it. But it shouldn’t– we don’t have to wait till it’s perfect, before we share it, because there are people in need.”* (Rory). It also tied to how well they maintain their innovations – for example, TV has worked hard to keep Emacspeak working through the times and the shifting world wide web.

Our innovators’ desire for real-world impact meant their innovations needed to work across a range of contexts – and they found that this would require change on the world’s part as well. When mediating access to existing technologies, businesses, and practices, they found that these institutions often upheld norms related to ability. For example, TV shared that text-to-speech engines continue to value naturalness of voice over the intelligibility at higher speech-rates, which is more important to nonvisual access use cases. Similarly, Ed spoke about how sonification requires extracting relevant data from existing images– a significant challenge they encounter is that *“the data visualizations that exist in the world, regardless of how they’re created, as a rule, they don’t have the information required to drive nonvisual access methods.”* (Ed). Recognizing there was only so much they could do from the individual technology side of things, they took a multifaceted approach to accessibility, which we elaborate on below.

One thing our innovators thought was important to do was to counter misconceptions about disabilities, or more importantly misconceptions about disabled people’s needs and desires. While inaccessibility prevented people with disabilities from frequenting a space or a technology, their resulting absence from a space was not indicative of their lack of desire or interest in these spaces or technologies. Melissa shared her experience offering accessibility trainings to businesses: *“It’s very hard, honestly to sell the d/Deaf market matters because deafness is an invisible disability. [...] They don’t see it, so it’s not a problem they think needs to be corrected.”* (Melissa).

This motivated innovators to raise awareness about their communities. For example, Brendan shared a big part of what Caption-Fish did was that *“it created a movement that put butts in seats and showed theater owners [the Deaf community] had purchasing power.”* (Brendan). They were able to then use this to draw attention to discrepancies in the movie-going experience for Deaf attendees and call theaters to address them. Another interesting example is Rory’s experience with innovating the variable compliance joystick: they found that the demand for power wheelchairs increased by four times with its development because of how it allowed users to *“make [their] own choices”* (Rory) in moving about the world.

Innovators also countered subtle ableist rhetoric present in designed technologies. For example, Michael discussed some screenreaders simplified the computer interface and interactions based on their assumptions of blind people’s capacities. This resulted in constraining what blind users could accomplish with technology – *“blind people could never escape that environment”* (Michael). They countered this misconception in their approach to NVDA, designing it to afford users technical freedom and agency: *“It’s efficient*



*and fast. But it's still up to you how to use it. It doesn't tell you what to do, you control it.*" (Michael)

Apart from ignorance about disability, many existing technologies and platforms also simply left the work of access to others. For example, Michael shared that in order to mediate access to a wide-range of websites, old screenreaders had to be coded to account for every possible website design they might encounter. The result of this was fragmented, *"spaghetti-like"* (Michael) code. In designing NVDA, they decided to 'crip' these norms: *"We decided to write our code in a very different way. Very abstract, very modular, and most importantly, very standards-based. Which then, of course, starts to force other application creators to make sure that they make their products accessible as well and not just expect the screenreader to try and fix it for them."* (Michael). This standards-based approach shifts the burden of access work from accessibility technologies to all technologies, resulting in more robust code for screenreaders as well as increased web access for users. It is also exciting to note that in the many years since NVDA began, this approach has resulted in a paradigm shift in web accessibility.

We also see a similar multi-pronged approach taken by SoundPrint – along with helping users find quiet places, they also work with noisy venues to mitigate noise and prevent noise-induced hearing-loss. Both NVDA and SoundPrint's approach exemplifies not just facilitating access in the moment, but also about transforming the world at large. These innovators recognized the scalability of their ventures was tied to the sustainability of their approaches to access.

Taken together, our innovators' process of raising awareness, challenging misconceptions, and transforming the world highlights their dedication to long-lasting change. Ed shared, *"there's value, of course, in going off and creating things that are specific, quote unquote, 'assistive technology' products. But to do it in a way that is baked into stuff, all the stuff that everybody else uses– that's where we really change the game, I think."* (Ed).

## 5.4 Design Choices and Tensions

Many interesting design choices were informed by innovators' lived experience at large. For example, TV Raman characterized the programming approach he took with Emacspeak as 'programming defensively': *"this means that when a module breaks, it does not affect the rest of the system"* (TV Raman) [63]. Another interesting example is Greg's approach with SoundPrint – he discussed wanting to make the app accessible to people with a range of disabilities and access needs, and ensuring ease of use since many users may not be familiar with decibel meters. While one way to approach this would be to have more information on screen, Greg's life experiences drew him in a different direction. Tired of constantly having to guess what people said, he realized he gravitated *"towards people who are very succinct"* (Greg) in how they speak. In terms of SoundPrint, that meant he was *"uber focused on minimalism– the less information we communicate, the better. Because that's less work for the user to do"* (Greg).

In infusing their innovations with their values and making these design choices, our innovators also spoke of tensions they had to navigate. For example, NVDA's choice to be highly performant and efficient and not constrain users meant users faced a steeper

learning curve. Ed similarly discussed SAS graphics' commitment to preserving portability of skills and knowledge across graph types for users: this meant that while the rules of sonification and input commands stay consistent, it *"limits what you can do for particularly gnarly, difficult cases, you know?"* (Ed).

With DeafFriendly, Melissa shared her intention to always be working with d/Deaf and hard-of-hearing people: *"I believe in the ecosystem. You know, putting the money back into the d/Deaf community so that we can learn, grow and thrive together."* (Melissa). This unfortunately limited the pool of people they could work with, but she also found that communication was *"fluid and easy"* (Melissa) and they didn't have to worry about captioners and interpreters.

In honoring their values and lived experiences, our participants had to make choices that fundamentally changed their innovation design and process. However, our participants were aware of the trade-offs and were not in the pursuit of the perfect answer. Rory summarizes his perspective on design *"There's no right answer. There's no wrong answer. There's just different approaches to come up with various solutions"* (Rory).

## 5.5 Innovation and Empowerment

Lastly, we discuss what empowerment meant to our participants and how empowerment showed up through their experiences innovating as well as using accessibility technology.

Our participants spoke of empowerment that came from the technologies they built, for example in how it fostered access to technology or resources or physical spaces. Ed shared *"SAS Graphics Accelerator certainly empowers me personally to understand data [...] So having kind of access to quantitative information is incredibly empowering. But I think that's probably true for anybody who's adopted this to the degree that I have."* (Ed). In addition to this, Rory also spoke of *"empowerment more from the social and psychological perspective"* (Rory) – the technologies also facilitate access to opportunities like employment or education.

Others found empowerment in the process of innovating itself – for example, from overcoming barriers and noting their own perseverance and growth (Melissa). While many had experienced barriers to access in education, workplaces, and daily life, with innovating they noted shifting agency and power – agency in setting the norms for their own projects, and power to demand access needs be met first before moving on. Greg shared how he'd always been anxious about whether others would understand and meet his access needs in his career, but *"what's empowered me about SoundPrint and this app is that I'm driving the boat [...] there's other service professionals who want to help our company. So when I say I need XYZ [person] to do a FaceTime call to do this, there's less barriers to that."* (Greg).

Many also felt empowered by how they were able to support their communities. Michael's work with NVDA was deeply motivated by the desire to *"pay-it-forward"* (Michael) and ensure other blind people had the same opportunities and chances he was fortunate to have. Brendan shared a similar sentiment regarding CaptionFish, taking joy in how their innovation and advocacy had *"helped push for a more equitable movie going experience for the d/Deaf community."* (Brendan). Beyond the innovations Rory built for his own needs, he also spoke of how empowerment was something they sought to share through their work at HERL designing with other

disabled people: “We’re not here to help people with disabilities. We’re here to help people with disabilities learn to help themselves.” (Rory).

Lastly, innovators also spoke about how they felt empowered from the change they were affecting in the world. Melissa shared, “[When a business] invests in training and learns how to better communicate with me, I feel empowered. You know, because I see the value of what I have to offer is being received.” (Melissa).

## 6 Discussion

In sharing innovators’ stories, we cataloged the ways they provision access in an inaccessible world as well as the ways they work to recreate this world. Just by sharing their stories, we fulfilled a core tenet of disability culture—centering disabled people’s stories and celebrating their ingenuity. As Steve Brown said, “If you don’t tell your story how will the children learn?” [59]. We only touched on seven innovators out of many – we hope other scholars will continue the work of gathering and sharing these accounts. It is through these stories that we will be able to reimagine the future of accessibility and disability: “We learn so that we may deliberate, all of us together, about desirable futures. Who belongs in them, and why, and how, depends in part on the stories we tell about each other” (Sara Hendren) [23].

### 6.1 Disability and Technology: Connections to Prior Work

First and foremost, our gathered empirical accounts highlight that disabled people are not just *users* of accessibility technologies but also *creators* of accessibility technologies. Prior work has highlighted disabled people’s oft erased contributions to access by exploring individual practices of disabled hacking and modification (e.g., DIY-AT) as well as by calling researchers to attend to interdependent relations and co-creation of access [5, 6]. For example, Bennett *et al.* suggest crowdwork-based accessibility could be reimaged to value everyone’s contributions (disabled and nondisabled) and challenge ability-based hierarchies [5]. Our innovators’ stories (SoundPrint, NVDA, DeafFriendly) offer real-world examples of this idea and show the complexities of operationalizing these values of interdependence in technologies.

Second, our cultural analysis broadens conceptions of access and the role played by accessibility technologies. For example, consider how SoundPrint and NVDA build community and solidarity among disabled people (Section 5.1). Prior work by Hofmann *et al.* highlights the role of connections in shaping disability identity development and emphasizes the impact of storytelling in facilitating and strengthening connections between disabled people [25]. Our analysis shows that accessibility technologies themselves could also be designed to do the same, and thus also facilitate the cultural process of ‘claiming crip’. Similarly, our work complements Spiel & Angelini’s work on ‘cripping’ participatory design methodologies to value situated knowledge disabled people hold [57]. Our innovators’ stories show how technologies could be used to ‘crip’ the world at large (Section 5.3) and how deeply situated (crip) knowledge informs innovation processes (Section 5.2).

Overall, we situate our findings among calls to rearticulate relationships between disabled people and accessibility technologies. These innovators’ stories and our cultural analysis demonstrate

that cultural processes – such as finding community and a sense of belonging, developing and passing on knowledge, and discovering new ways of being – not only guide innovators’ lived experiences, but are central to how their innovations function. We believe this points to a new understanding of the relationship between disability and accessibility technology: the potential to consider disabled-led innovations as *artifacts of disability culture*. Through this lens, accessibility technologies created by disabled people act as a window into disabled people’s values and lived experiences, and can help us to reimagine our approach to accessibility technology design and research. The following two sections expand on this idea.

### 6.2 Reflecting Innovators’ Stories: Toward Liberatory Access

Our innovators emphasized the agency they had during their innovation process – how they were “*driving the boat*” (Greg), influencing all of the decisions in the process, big and small. As a consequence, we see their innovations go beyond simply facilitating access in the moment to achieving larger goals and embodying different values, as we have showcased in the results. Here we reflect on their values further:

*Increasing Autonomy.* While increasing access to physical and digital spaces is a goal shared by many, we see these innovators aimed to do so in a way that allows disabled people to “*make their own choices*” (Rory) in exploring and engaging with the world at large. We see this in Rory’s example of independent mobility fostered by the variable compliance joystick – power wheelchair users can choose when and where they want to go. We also see this in how NVDA places no restrictions on what users can do with their screenreaders, making no assumptions about blind people’s capabilities or interests. SoundPrint and DeafFriendly foster access to information about accessibility of venues, allowing them to choose what they have capacity for on a given day. More broadly, the increased access to information (e.g., data through SAS Graphics Accelerator, the web at large with NVDA and Emacspeak) helps users recognize the choices they have and informs the decisions they make across multiple domains of everyday life.

*Sharing Power.* Our innovators were uniquely positioned with their knowledge – be it technical expertise, leadership, or creativity – to create something to address their access needs. The resulting innovations helped them reclaim their power by increasing access and autonomy. And they also felt empowered through the *process* of innovating, recognizing the skill and agency they had to address the very issues that impact their lives. Notably, these innovators were committed to sharing what they built with other disabled people, thereby extending this empowerment as well. Users of their access technology were empowered by the access mediated by the innovation as well as by their ability to *contribute* to access (e.g., the open-source nature of NVDA and the hundreds of BLV contributors as well as the crowdsourced data of SoundPrint and reviews of DeafFriendly). Additionally, along with empowerment snowballing from innovators to users, we also see that the pathways for redistributing power multiply. Consider the information shared about accessibility of venues or deaf friendliness of businesses–

users can use this to decide where to spend their money and affect change through collective consumer power.

*Affecting Structural Change.* These innovators expanded the scope of their work from just making a website or business accessible to exploring what series of societal transformations would make this access *sustainable*. Instead of just focusing on the technology, they explored the infrastructure technology exists within – working to change factors that shape access technologies’ availability, affordability, and adoption. We see this in history as well: access to Braille and TTYs required significant activism from the community and policy reform. And with increased adoption, they fundamentally changed how disabled people live and connect with one other. The examples in Section 5.3 demonstrate our present innovators’ commitment to challenging the status quo (e.g., NVDA’s standards-based approach). These innovators had to contend with the different pace and different workings of this larger sociopolitical infrastructure (education, law, economics) – for example, while Braille is now accepted in the education establishment, sonification is still fairly new and it will be some time before it is taught in schools.

Our innovators’ stories highlight their deep knowledge of the multiple mechanisms by which inaccessibility and ableism materialize. Guided by this and their lived experiences, they wished for their access technologies to go beyond creating ways to “*squeeze into able-bodied people’s world*” (Mingus) [43] to also work to address the broader conditions that create inaccessibility in the first place. In this approach, we see echoes of what disability justice activist and scholar Mia Mingus calls *liberatory access*. Instead of just working towards inclusion and assimilation, liberatory access strives to challenge the broader conditions of able-bodied supremacy and exclusion. This also echoes Steve Brown scholarship on disability culture [11] – wanting disabled people to be a part of society *as they are* and not conforming to non-disabled ways of being. Our innovators’ approach to accessibility (“crip-made access”) embodies these values of transformation and liberation – working to increase autonomy, share power, and affect structural change. They treat access as work of collective change rather than an individual state of affairs. We see that their approach transforms access technologies into larger tools for change and connection: making screenreaders into a movement, a decibel meter into a community.

### 6.3 Reflecting on Directions for Accessibility Research

We find that the accessibility technologies created by people with disabilities not only reflect values important to their innovators, but are also a place where questions of crip identity and community and knowledge and cultural imagination play out. These stories serve as evidence of the generative power of disability culture, and inspire us to rethink the goals and values we imbue in the accessibility technologies we design. In this section, we reflect on directions for future research.

One direction is to deepen our understanding of disability culture and disabled people’s values by attending to a larger set of disabled innovation practices (and not just disseminated technologies). For example, we can explore how disabled people are negotiating

questions of identity and community and knowledge and agency through their practices of hacking, adaptation, modification. We could also explore how disabled people are hacking or modifying their ‘traditional’ accessibility technologies to better align with cultural values and we could examine how lack of alignment with these values results in not wanting to use AT.

Another direction is to explore how accessibility technology could be designed to enable cultural goals and processes. Mediating access barriers will always be a crucial guiding component in our work as accessibility technology researchers. But disability culture and liberatory access show us that one of the most powerful ways to combat ableism is to *value* disability– “*not running from disability but moving towards it*” (Mia Mingus) [43]. How can we lean into disabled ways of being, and create tools that *also* foster deeper connections between disabled people and challenge oppression? Below we outline some ideas:

*Negotiating Disclosure.* Examples in Section 5.1 highlight the ways accessibility technology can facilitate finding community and building solidarity. This then helps disabled people claim disability as a political identity i.e., helping them recognize that disability exists in the context of widespread ableism. Perhaps another way we might take inspiration from this approach is to deepen our exploration of disability disclosure through accessibility technology. For example, much of the discourse about visibility of accessibility technologies has been about how they might identify and stigmatize people with disabilities. But sometimes visibility also lends credibility to disabled people’s need for accommodations and reminds interlocutors to meet their access needs [18]. Researchers have begun to explore disabled people’s practices decorating their accessibility technologies, shifting from the medical to the aesthetic and expressing pride in their identity (e.g., [14, 47]). Could visibility perhaps also help disabled people meet others like them and thereby enable disabled connection and organization?

*Non-Disabled Contributions to Access.* The crip repositories of knowledge we highlight in Section 5.2 are an incredible resource not only for disabled users and disabled contributors, but also in how they bring in non-disabled people. Many have expressed that the work of access cannot all be on disabled people. One interesting body of work explores how the responsibility of meeting access needs can be shared amongst all present (e.g., [38]), and these are powerful in negotiating access in group contexts. However, (solo) work of non-disabled people to support access (even with the best intentions) has historically perpetuated misconceptions about disability and further harmed disabled people (e.g., empathy and proxies [6], disability dongles [36]). SoundPrint (amongst other crowdsourced platforms like YouDescribe<sup>12</sup>) illuminate an interesting approach for these contexts – they leverage the collective power of the masses (*anyone* can contribute to access) but disabled experiences and knowledge are the foundation of the design. This means the platforms guide individuals to contribute information that’s actually useful to people with disabilities. Interestingly, their approach also has the potential to shift how non-disabled people perceive the world, drawing their attention to systemic ableism and

<sup>12</sup><https://youdescribe.org/>

inaccessibility. This helps them understand disability not as a individual deficit but also as societal barrier, slowly getting “*able-bodied people to inhabit our world*” (Mingus) [43].

*Crippling Norms.* Our innovators’ multi-pronged approach to accessibility Section 5.3 highlights an approach to access that “*lives in the now and the future. [...] It is a way of doing access that transforms both our ‘today’ and our ‘tomorrow.’*” (Mingus) [43]. It inspires us to expand our goals of our work from addressing barriers in the moment to exploring how we might impact long term infrastructural and rhetorical changes. This is necessary to ensure sustainability of our technologies, but requires further contemplation. Crippling norms and standards is an interesting approach here, but how can we do this in a way that doesn’t obstruct access in the present (i.e., companies just not complying with accessibility standards and thus excluding disabled users) but also incentivizes long term structural change (i.e., not just assuming the accessibility technologies will fix it for them)? The tensions between the immediate need for access and the long time it takes to affect structural change point to the need to set a diverse set of goals as a field– with some working on dynamic access and some working on sustainable longitudinal solutions. It also point to the need to look beyond academia and build coalitions with disability advocacy organizations, law and education and policy groups to increase our capacity for real-world impact.

## 6.4 Limitations and Future Work

The cultural lens we have proposed here should be developed further. Our cultural lens outlines three aspects of disability culture, but these are not exhaustive or comprehensive. Different orientations to culture might offer new axes to consider and deepen our understanding of the phenomenon. Second, our synthesis of disability culture is primarily based in literature and accounts from Global North in the last century – as culture is always situated in a time and space, these aspect might occur differently in different regions and may evolve over time. Third, disability intersects with many other identities and therefore many cultures (e.g., queer culture, Black culture) and it is important to trace shared genealogies and commitments. It would also be interesting to explore how people navigate the many cultures they are a part of (e.g., regional culture and disability culture, or disability culture and queer culture). Fourth, our analysis was also influenced by sample of innovators – examining how these cultural themes present in a wider range of innovations and accessibility technologies is a valuable direction for future work. Lastly, while much of this work has focused on disabled creativity and pride, we also recognize that disability, and therefore disability culture, encompasses harm as well – these multi-generational traumas might be expressed in grief, shame, and similar concepts. We encourage researchers to explore how people move between these facets and tensions that might arise.

## 7 Conclusion

In this paper we explored disability culture and how it might inform the design and research of accessibility technologies. After tracing disability culture, we presented accounts of seven innovators of accessibility technologies, and contextualized their design choices through the lens of disability culture. We found that this cultural

lens helped us look beyond the framing of ‘access barriers’ to also recognize how accessibility technologies might help foster community and build solidarity between disabled people, document and share crip knowledge, and transform the world. These disabled innovators exemplify a liberatory approach to access– embodying goals of increasing autonomy, sharing power, and affecting structural change. We propose that accessibility technologies designed by disabled people be considered as artifacts of disability culture, in how they both embody cultural values and facilitate cultural processes. We hope other researchers are inspired to ground their work in disability culture and reimagine accessibility technologies to transform the world – bringing us closer to a world that welcomes disability.

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