Understanding, Designing, and Building Adaptable Technology for Fluctuating Accessibility Needs in Group Settings

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Abstract

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Many people with disabilities have access needs that must be met to have fully accessible group interactions. Accessible technologies often offer a one-size-fits-all solution, or they require the user to perform a calibration process to adjust the technology to meet their needs, which can be time consuming and burdensome. In this dissertation, I demonstrate that creating an “accessible experience” for a group is a constantly fluctuating ideal, since several dynamic factors impact access provisioning. These factors include variations in individual ability, social contexts, spatial contexts, and the visibility of a disability. Through three studies, I characterize these factors and how they interact to impact what it means to make a group interaction accessible. Finally, I demonstrate how to design a system that accounts for fluctuations in access provisioning. I designed and tested this system in the domain of slide deck presentations, finding that technology allowed multiple people’s access needs to be met at once, which was previously infeasible due to a lack of presenter time and expertise.

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Chapter 1

INTRODUCTION

Consider a group of three college students who are meeting for a group project, El, Yuxuan, and James. This team has worked together before, and knows that it is important for their group meetings to be accessible to everyone. One student, El, is hard of hearing and uses real-time captions or speechreading[1] with their hearing aids to engage in synchronous, in-person conversations. They prefer lipreading, to better see their group members' facial expressions. So, the group plans on meeting unmasked in a well-lit space to allow for easy lipreading. The group members all take COVID tests before meeting indoors unmasked, since Yuxuan has a chronic illness and is higher risk for COVID complications.

When they hold their meeting, everything goes according to plan, until the batteries to El's hearing aids die. They cannot lipread as effectively without their hearing aids. The group stops what they are doing and evaluates. The project is due the next day, so they cannot afford to wait and reschedule to another day when they can have a CART captioner[2]. They decide to open Google Meet, which has automatic speech recognition (ASR) and creates AI-generated captions. These captions have errors and are delayed compared to the speech, and sometimes crash altogether for several seconds at a time. To maintain access with the technological limitations, James volunteers to monitor the captions to make sure they are working and accurate. All group members agree to allow ample pauses before responding so that El has a chance to voice their opinions when the captions catch up. The meeting continues, and the group finishes the project before the deadline.

If we take a step back and analyze this situation, we notice some elements that were core in provisioning access. The group members prepared to make the meeting accessible by COVID testing in lieu of wearing masks and meeting in a well-lit space to support Yuxuan and El's access needs.

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[1] As defined in the dictionary as: "the act or process of determining the intended meaning of a speaker by utilizing all visual clues accompanying speech attempts, as lip movements, facial expressions, and bodily gestures, used especially by people with hearing loss."

[2] A professional who joins the meeting and provides near real-time transcripts of what is said.

However, when El's hearing aids turned off, they decided to adopt new communication norms and use the technical solution (ASR) over the constrained non-technical resource (CART). Together, all of these factors allowed the meeting to run smoothly and accessibly, even when circumstances surprisingly changed in the middle.

1.1 Factors for Provisioning Group Access

This example demonstrates that there are a multitude of factors that are constantly changing and therefore keep redefining what shape an accessible solution takes in group contexts. In chapter 4, I demonstrate that provisioning access does require 1) **preparation**, or consideration beforehand of how a group interaction will be made accessible, and 2) **adjusting** when factors that impact accessibility change in-the-moment.

Understanding how to **prepare** for accessible group interactions has been highly studied and documented in public policy, HCI research, and in community settings. Checklists of best accessibility practices exist for websites, events, and classrooms. For example, lists of accommodations for teaching accessibly [DO-IT, 2023, DO-IT, 2013], hosting events accessibly [Invalid, 2017], and conducting research accessibly exist [Coyne and Nielsen, 2001, Mack et al., 2022a]. Tools can often support these efforts (automatic alt text, WCAG checkers, color blind friendly palettes/templates). These checklists and tools are helpful at the preparation step. Yet, preparation only goes so far, and once events are underway, adjusting the scenario to meet emergent needs is critical.

Much less work focuses on how to support people in meeting emergent, rapidly changing access needs. Thus, in this dissertation, I first focus on understanding how factors that impact access provisioning fluctuate through learning from the lived experiences of disabled individuals. I argue that by understanding these factors deeply, technology designers are better equipped to build systems that can *adjust* to meet in-the-moment changes without overburdening disabled users. More formally, I investigate the research questions:

- What are the individual, social, and environmental factors in group settings that fluctuate and impact access provisioning? How do they tend to fluctuate?

- Informed from these factors, how can we better design technologies so that can adjust to meet fluctuating access needs in group settings?

To answer these questions, I performed studies that engage with HCI accessibility experts, disability community organizers and activists, and disabled communities. Specifically, I sought to to understand how access can fluctuate in group settings and how people in groups work together with technology to create access. Finally, I demonstrate how technology can meet multiple, bespoke access needs at once through designing and testing a tool that creates customized versions of shared materials (specifically, digital slide decks). Combined, this work demonstrates the thesis:

> Creating access for a group of people is dynamic due to fluctuations in individuals' abilities and the social dynamics and overlapping access needs of the group. In group contexts, technology that utilizes automation to customize shared materials to meet individual needs can allow multiple sets of access needs to be met at the same time in scenarios where it was not previously feasible.

1.2 Research approach and contributions

Throughout the studies presented in these chapters, I performed formative, qualitative research with disabled communities. I then took the findings and demonstrated their social and technical implications by developing and testing a system that support groups with diverse ranges of access needs in provisioning access.

In chapter 3, I describe how a chronically' ill person's individual abilities can fluctuate greatly and impact how they want technological support. While existing research understands that different people might have different needs [Mott and Wobbrock, 2019, Mott et al., 2016, Gajos et al., 2008, Gajos et al., 2007], it studies much less how a single individual's needs can change overtime. Through engaging with the documented expertise of chronically ill communities, activists, and scholars, I propose tenets for how to design for chronically ill bodyminds, focusing on how technology can support bodies whose needs change drastically over the span of days or even hours.

In my next two chapters, I focus on understanding how social factors, including social and spatial contexts, interact to impact access. To do so, I studied access in settings with varying-sized groups with mixed-abilities or all disabled people. First, in chapter 4, I conducted interviews with experienced HCI practitioners and disability community organizers who work with disabled participants, some of whom are disabled themselves. I asked them how they provision access during studies and related events (e.g., focus groups, surveys, interviews, events). I then define a core framework of approaching access with “anticipation and adjustment,” which conveys that, taking time to thoughtfully prepare for access is crucial, but so is being flexible and adjusting in-the-moment as factors that impact access fluctuate. Then, to complement this perspective, I used autoethnographic methods in chapter 5 to analyze my experience of creating access while on an accessibility-focused research team at Microsoft Research. I identified how our traditional ways of provisioning access needed to adjust due to new factors during our internship: the virtual context, the conflicts between access needs, the difficulty in remembering and implementing a long list of accommodations, the power dynamics at play, and the role of allyship.

Then, I designed and tested a system that can meet multiple different (even conflicting) access needs in a group setting simultaneously. More specifically, in chapter 6, I designed a slide deck plug-in that allows each audience member in the presentation to easily make changes to their own copy of the presentation slides to meet their access needs in-the-moment. I then tested the use of this software in a live presentation setting to understand if the solution works in-situ, and to understand the impact of having multiple different versions of the same shared resource in use at once. This research identifies the utility of technology that is designed to support fluctuations in access needs and access provisioning. But also, it highlights the added logistical complexity of such a paradigm and the consideration that must be made for the rights and agency of the slide deck author.

Finally, in chapter 7, I bring these fours sets of findings into conversation with each other and present a set of factors to guide the design of accessible technologies in group contexts. I also enumerate directions for future research based on what I uncovered in this dissertation.

1.3 Positionality statement

I gravitate towards using qualitative methods because I like to examine the messy nuances of life that make humans human, which can be lost when reducing experiences to data points. These rich experiences are inevitably oversimplified with any method, including in this research. While I mainly focus on disability, chronic and mental health conditions, and neurodiversity in people’s lives, the people in these communities are whole rich people beyond their disabilities or related conditions, the full extent of which is not captured in this work.

Finally, I recognize that my own identities influence how I approach creating and presenting themes from the qualitative data that participants share with me. Namely, while conducting this research, I am a white student with the immense privilege of working at a large public university with a considerable research community that focuses on accessibility. I am English-speaking and am living and working in a Western, English-speaking country (Washington in the United States). This privilege positions me further away from the experiences of many of my multiply minoritized participants (e.g., disabled people who come from a minoritized linguistic, racial, or ethnic background). I also identify as chronically ill, disabled, and queer, and since coming to Seattle, have found a deep sense of disability pride. I recognize that not all people share a pride in, or even affinity with, a disability identity (or have the privilege and safety to do so), as disability is still a stigmatized topic and identity across the world. Combined with my own experience with critical disability studies and exposure to disability justice, I approach disability topics with an eye for celebrating disabled joy and the creativity and resilience of disabled people in hacking the world around them [Hamraie and Fritsch, 2019]. At the same time, I look critically at hegemonic systems of oppression that label bodyminds as abnormal and therefore worse, as well as capitalistic systems that valuate bodyminds based on their ability to produce in normative ways [Davis, 2013].

Chapter 2

RELATED WORK

In this section, I first define key terms and concepts that are used throughout the chapters, including access/accessibility needs, crip time, interdependence, and collective access. Then, as this dissertation focuses on developing technology to meet the fluctuating access needs of groups, I provide an overview of 1) the literature that focuses on key factors of group interactions that impact access provisioning and 2) the existing literature of how technologies can support fluctuating abilities.

Thieme et al. and Bennett et al. highlight the importance of viewing the full context in which a disabled person exists to understand how to fulfill access needs, with Thieme framing "(dis)ability as produced through interactions with the environment and configured by the people and technology within it" [Thieme et al., 2018, Bennett et al., 2018]. Consequently, I summarize the field of HCI accessibility research's work on the topics of social context implications for accessibility (e.g., power dynamics), spatial context implications for accessibility (e.g., virtual versus in-person, global context), and the (in)visibility of disability (e.g., disability disclosure). While prior work studies many of these factors in isolation, my work investigates the interplay between these factors and provides new insights around how they fluctuate and impact group access provisioning.

Finally, I conclude by summarizing the design paradigms around creating technologies that adapt to meet users' needs, and I cite several examples of systems that embrace this practice. Ability-Based Design is one of the most notable paradigms for building technologies that adjust to meet the user, rather than requiring the user to change to use the technology [Wobbrock et al., 2011]. I build on this work by more formally codifying different factors that can impact access provisioning, and I focus mainly on a group context. Finally, many existing systems rely on using a lengthy tuning phase to customize the system to meet user needs, which is often assumed to occur once when the system is first adopted. My work proves that abilities and other factors impacting accessible technology use fluctuate quickly, on the time span of even minutes. Therefore, I argue that technology needs to be able to react nimbly and easily throughout the day to best meet user needs, and I suggest how technology can be built to do so.

2.1 Key Terms and Definitions

For this dissertation, I employ the term "*access needs*," or synonymously "accessibility needs," as defined by Disability Justice movement leaders:

> "Access needs are those things that are needed in order for someone to fully participate in a space or activity, which can include wheelchair access, scent-free space, ASL interpretation, etc. In a disability justice context, access needs are seen as universal - every bodymind has needs, not just disabled people."

Therefore, when I describe making an interaction or space "accessible," I refer to the practices that are done in service of meeting participants' access needs.

Oftentimes, the access needs that I focus on are those of people who identify as disabled, chronically ill, neurodivergent, or have a mental health condition. This group can include people who receive formal accommodations necessitated by the ADA or Section 504 of the Rehabilitation Act [U.S. Congress, 1990, U.S. Congress, 1973] regardless of their adoption of any kind of disability or related identity. Throughout this dissertation I use a combination of person first language (a person who is neurodivergent) and identity first language (a neurodivergent person), recognizing that people in the disabled communities that this work aims to serve prefer both for valid reasons [Sharif et al., 2022]. Many of the ensuing chapters focus specifically on groups, and I use the term "group accessibiltiy" to refer to the process of fulfilling all, or as many as possible, access needs for all individuals in the group, such that the group can perform its intended task.

2.2 Concepts from Disability Studies and Disability Justice

Disability studies is the academic discipline of critically analyzing how society defines and treats non-normative bodyminds. Disability studies scholars developed a key concept that I use throughout my studies, "crip time," which theorizes about the different temporalities (or, experiences of the passing of time) in which disabled people and people with access needs operate. Allison Kafer, in first formalizing crip time, imagines its power: "*rather than bend disabled bodies and minds* *to meet the clock, crip time bends the clock to meet disabled bodies and minds*" [Kafer, 2013]. Ellen Samuels, a chronically ill disability studies scholar, calls attention to the ways that crip time simultaneously provides tools to imagine a more accessible future while highlighting that rigid, normative expectations of life paces can be sites of painful inaccessibility [Samuels, 2017].

Throughout this dissertation, I also pull on core concepts from Disability Justice, an activist movement lead by queer, trans, black, indigenous, and other people of color that pushes for transformative justice to ensure access for people with disabilities. It is a movement that is based on 10 principles, penned by Sins Invalid, a performance collective that is comprised mainly of queer people of color, and is dedicated to progressing Disability Justice. In this dissertation, I mainly pull from two core principles: interdependence and collective access. Disability activists and disability studies scholars have applied these concepts as a useful framing in analyzing how to create access with and without technology [Benness, 2019, Mingus, 2017, Piepzna-Samarasinha, 2018].

Interdependence, in the context of disability, often refers to the practices of groups of people mutually fulfilling each others access needs. Lakshmi and Mingus detail an activist perspective of how disabled people create care networks to survive and advocate for justice, which relies on people offering up their needs and the types of supports they can provide others [Piepzna-Samarasinha, 2021, Piepzna-Samarasinha, 2018, Mingus, 2017]. Mingus further details "*that elusive, hard to describe feeling when someone else 'gets' your access needs*," for which she uses the term "access intimacy" [Mingus, 2011]. Interdependence is not limited to human actors; an interdependent system can involve the environment and other tools, like technology. HCI scholars Bennett et al. demonstrate how adopting a lens of interdependence highlights that adaptive technology is not the full access solution; the full concept of creating access varies and relies on other components like other people and the environment [Bennett et al., 2018].

Collective access refers to "reframing access needs as belonging to, and the responsibility of, the group, rather than an individual," [Invalid, 2019]. Technology can embrace this principle and work to create dynamics where "access labor" is shared by individuals and the system, rather than lying solely with the disabled individual [Das et al., 2019, Branham and Kane, 2015b]. For example, some HCI works document how groups do (or do not) effectively co-create access. They offer design suggestions for technologies that encourage conversation around access and shared responsibility of the access labor [Baldwin et al., 2019, Wang and Piper, 2018, McDonnell et al., 2023].

2.3 Social Context's Impact on Creating Access

Research on mixed ability interactions highlights that access is not independent from social context: social dynamics can create tensions that limit or promote access. Disabled coworkers may be hesitant or feel guilty to voice needs because of the expectations and perceptions of nondisabled colleagues [Branham and Kane, 2015b], especially when there are unequal power dynamics involved [Das et al., 2019]. Relatedly, neurodivergent people oftentimes are forced to "mask," or change their behavior and appearance to avoid harm, with neurotypical people or else face judgement or bias [Miller et al., 2021b]. Masking is known to be an effortful action that has strong negative consequences for the mental health of neurodivergent people, and at a minimum, can make the space feel less comfortable for them [Miller et al., 2021b].

Prior work often investigates how people with one specific disability and nondisabled individuals interact in different circumstances. In line with HCI accessibility trends [Mack et al., 2021c], this work overwhelmingly focuses on people who are blind or low vision interacting with sighted people in different contexts including shopping [Yuan et al., 2017], navigating and way-finding [Vincenzi et al., 2021, Williams et al., 2014], playing video games [da Rocha Tomé Filho et al., 2019, Gonçalves et al., 2021], story telling [Cullen and Metatla, 2018, Cullen and Metatla, 2019], educational contexts [Metatla and Cullen, 2018, Metatla et al., 2019, Thieme et al., 2017], writing [Das et al., 2019, Das et al., 2021], creating and managing a household [Branham and Kane, 2015a], photo sharing [Mathur and Brady, 2018], and paddling [Baldwin et al., 2019]. Work is starting to examine other populations, including looking at how DHH [Wang and Piper, 2018] and neurodivergent [Morris et al., 2015, Zolyomi et al., 2018] people work with nondisabled colleagues in educational and work environments, and virtual interactions between neurodivergent and neurotypical individuals [Ringland et al., 2016, Ringland, 2019, Zolyomi et al., 2019].

While most prior work focuses on mixed ability groups with only one disability represented, the autoethnographic accounts of disability justice activists and academic disabled scholars emphasize how common cross-disability interactions are. Lakshmi describes "care networks" of people working interdependently to meet the needs of each of their members [Piepzna-Samarasinha, 2018], where oftentimes few or no members are nondisabled. For example, Jain et al. explain their experiences creating "uncharted accommodations" for people with different disabilities and access needs, like someone who is blind and someone who is hard-of-hearing [Jain et al., 2020]. Hofmann et al. further delves into this topic, describing how disabled authors "co-exist together despite conflicting needs" based on their experiences of a chronically ill and blind person co-navigating. At the same time, they demonstrate how access needs can synergize within the same scenario (e.g., a blind person can offer a stable arm to an unsteady, sighted navigator) [Hofmann et al., 2020]. Though, some research is starting to investigate how technology can support mixed ability teams with multiple disabilities represented within the group. Zeynep et al. studied a mixed ability team in Turkey, focusing on how they created access for the team's project in a virtual workplace. Based on their findings, they encourage tools to promote accessibility by working to mitigate power dynamics as well as support the multiple languages and cultures of its users [Yildiz, 2022]. However, overall, there is a lack of work looking at these dynamic, often complex ways of creating access with multiple disabled individuals.

While technology can be a useful tool in helping provide access for mixed ability teams, Thieme et al. cautions to be conscious that technology not seek to replace all forms of access provision, as access between humans can be an intimate, meaningful form of connection [Thieme et al., 2018], echoing Mingus' concept of "access intimacy" [Mingus, 2017]. Further, prior work explains that creating access in a collaborative team is hyper-specific to the context at hand and therefore is often changing, so access often needs to be renegotiated over time [Wang and Piper, 2018, Branham and Kane, 2015b]. Together these papers indicate that teams and technologies need to be intentional to create accessible spaces that align with disability justice principles of interdependence and collective access; they will not come by default.

Power dynamics can affect how comfortable people feel asking for accommodations [Shinohara et al., 2021]; indeed, the process of weighing potential social cost against the accommodations' benefits can require considerable emotional labor [Das et al., 2019]. A common power structure involves a person with access needs advocating for accommodations to a person in power (e.g., a boss [Das et al., 2019], an advisor [Shinohara et al., 2021]). Das et al. found that accommodations in a group meeting were often not dictated by access needs of the group so much as the preferences of the person with the most power [Das et al., 2019]. When accommodations were not made, it left people with access needs needing to work more and harder for potentially worse results than peers who were nondisabled or fully accommodated [Das et al., 2019]. On the other hand, when people with access needs were in power, they could set a standard of valuing access practices [Das et al., 2019]. Zeynep et al. describe a different set of power conditions where a team of disabled workers needed to negotiate with nondisabled external collaborators. They found that teams that included disabled members needed to "balance their access needs and requirements of being a 'professional' team that 'integrated well' with external collaborators while balancing ingroup and outgroup tensions," [Yildiz, 2022]. Finally, researchers have explored how to negotiate power dynamics in research settings, especially in participatory design, where a researcher's role inherently provides them power over participants [Bratteteig and Wagner, 2012]. Specifically within an accessibility space, Spiel et al. worked thoughtfully to develop procedures that increased the power and agency that autistic children participants had in determining the direction of the research [Spiel et al., 2017]. In social contexts with power hierarchies, how power is distributed has a considerable impact on if and how access is provisioned, and at what social or emotional cost.

2.4 Spatial Context's Impact on Creating Access

Where a group or person is situated can influence how accessible the experience is. Different spaces offer different accessibility challenges and affordances, which can necessitate different ways of engaging with assistive technologies. For example, a person might choose to navigate with a guide dog inside their home and a white cane outside the house. Similarly, different spaces present different sensory experiences, which can create or hinder accessibility for people who have sensory related disabilities (e.g., Autism) [Zolyomi et al., 2019]. However, these factors are not immutable; accommodations can be made to improve the sensory experience for its occupants. For example, Johansson et al. put tennis balls on the bottom of all tables and chairs to minimize unpleasant noises during their reseach study [Johansson et al., 2015]. Sensory aspects of a space, like lighting, can affect other communities beyond neurodivergence, including people who are chronically ill or DHH people. Notably, DHH communities created the concept of DeafSpace, which are spaces specifically created to embrace Deaf norms [Edwards and Harold, 2014]. Practically, part of designing for DeafSpace involves designing spaces to support sign language communication, like maximizing natural light and creating unbroken sight lines (e.g., not having pillars in the middle of open spaces). Research and activists noted that doing the work to make a physical space accessible can be a builder of trust or access intimacy for people with access needs [Mingus, 2017, Johansson et al., 2015].

The accessibility of virtual contexts has been an increasingly popular context to study, especially since the COVID-19 pandemic starting in 2020. During this time, teleconferencing systems became increasingly popular, and their access tools evolved drastically. Tang investigated the accessibility of teleconferencing systems for people with a variety of access needs. He found that some access barriers were removed in a virtual setting (e.g., neurodivergent people could turn cameras off and worry less about visual impression management; people with mobility disabilities did not need to craft routes into inaccessible spaces) but also introduced new barriers (e.g., increased difficulty lip reading, or audio overload from meeting and screen reader audio coming from the same channel) [Tang, 2021]. Further, other work focuses on how meeting communication can become more or less accessible in virtual spaces, often depending on meeting participants' behaviors and attention to accessibility norms [Rui Xia Ang et al., 2022, McDonnell et al., 2023]. Das et al. and Zolyomi et al. describe how neurodivergent teleconference participants often need to work to manage the amount of sensory and cognitive overload that they might experience from their physical and virtual environments through coping strategies. These strategies ranged from negotiating for accessible communication practices and maximizing the sensory comfort they can experience in their physical location [Zolyomi et al., 2019, Das et al., 2021].

Finally, while the prior studies mostly discuss the concept of "location" in terms of being at a park versus on a zoom call, geographic location is another important determinant in how to provision access. Notably, different geographic locations often vary in culture and attitudes around the concept of disability itself [Ingstad, 1995, Rao, 2001, Suharto et al., 2016, Berghs, 2017, McEwan and Butler, 2007]. Therefore an access solution that is effective, but calls considerable attention to a person's disability might be eschewed for a less accessible but more privacy preserving solution in a location where there is more cultural stigma around disability. Much of the work in this dissertation is situated in a US-based context, and many participants bias towards having disability pride rather than seeking to hide their disabilities. While other geographical (and cultural) contexts, are not the focus of this work, they are critical to better understand, and emphasize how important of a factor *visibility* is in creating access solutions.

2.5 The (In)Visibility of Disability

People with disabilities have nuanced personal experiences with navigating disability identity, visibility, and disclosure [Shinohara and Wobbrock, 2016, Davis, 2005]. In a world where people are questioned around if they are "really disabled" or "disabled enough," visible signifiers of disability like assistive technologies can provide a way of "legitimizing" their disability identity [Profita et al., 2016] (especially when seeking accommodations), and meeting dominant nondisabled assumptions of "what you see is what you get" [Davis, 2005]. Though, making disability visible opens individuals up to harms from stigmatizing views from other people in the space [Shinohara and Wobbrock, 2016]. While some aspects of disability are more static in their visibility to others (e.g., a limb difference), others can change based on a person's needs and the social context. For example, Faucett et al. recount that some people prefer not to show symbols of chronic illness, less they then be treated as patients before anything else [Faucett et al., 2017]. As Hofmann et al. explain, for some disabled individuals, they "fluidly transition from states of visibility and invisibility," based on the circumstances at hand [Hofmann et al., 2020].

Beyond assistive technologies, many common technologies (e.g., teleconferencing platforms) can affect the visibility of disabled people and disabilities. For example, Tang found that in video calls, some people wanted to turn their video off because they were BVI or to they wanted to limit distraction [Tang, 2021]. However, turning of their video feed then relegated their avatar to being an impersonal avatar silhouette. Thus, meeting their access need (less visual stimulus, not wanting to mask) rendered them nearly invisible in the virtual context. At the same time, the virtual context allowed people to hide aspects of their disability if they wanted to; for example, a person with Tourette's Syndrome was able to not show a tic during the call [Tang, 2021].

2.6 Designing for Ability Variability

Disability is often not a static reality. The experience of having a disability can vary significantly between individuals with the same diagnosed disability. Even within an individual, abilities can fluctuate over years, days, or minutes [Benness, 2019]. Some technologies and design paradigms aim to recognize and meet fluctuating access needs. One strategy of "design for disability" is Ability-Based Design, which aims to "universally apply "design-for-one"" strategies [Harper, 2007, Wobbrock et al., 2011]. Notably, Ability-Based Design lays out a set of principles that technology designers can implement towards a goal of "create[ing] systems that leverage the full range of human potential," [Wobbrock et al., 2011]. This approach centers users' abilities, rather than disabilities, and uses technology to sense and identify users' current abilities, and adapting technology to meet needs.

Whether explicitly claiming the label "Ability-Based Design" or not, several projects work towards this goal of being highly customizable to meet the unique abilities and preferences of a large range of people. A set of works has focused on taking ubiquitous interfaces and adjusting them to be usable by a variety of people and myriad assistive technologies [Loitsch et al., 2017, Gajos et al., 2010] (e.g., people who are blind or low vision [Bigham et al., 2008, Kane et al., 2008, Zhang et al., 2017] and people who have mobility disabilities [Mott and Wobbrock, 2019]). Other works focus on taking a type of accessible technology and making it hyper-customizable to better attune to users preferences and abilities. For example, prior work built custom systems for sound recognition for DHH people [Jain et al., 2022, Goodman et al., 2021] and tactile maps for navigation for blind and low vision people that match their abilities and interests [Hofmann et al., 2023]. These works most often focus on customizing a system at the start to be personalized to an individual when they set up the device. While some work touches on continuous customization (e.g., [Goodman et al., 2021]), most work does not address customization overtime for a single user, especially on the time scale of days or hours.

Chapter 3

VIEWING PEOPLE WITH CHRONIC ILLNESSES AS HAVING FLUCTUATING ABILITIES AND ACCESS NEEDS

This chapter is based on [Mack et al., 2022b] (screen reader accessible).

3.1 Introduction

Billions of people around the world [Boersma et al., 2020, Hajat and Stein, 2018] are diagnosed with chronic illness, broadly defined as a range of conditions and diagnoses that impact functioning and are not expected to go away or be immediately fatal [Crow, 1996, Wendell, 2013, Patsavas, 2014, Price, 2015, Reynolds, 2017, Goering, 2015]. Chronic illness is an interesting site to study fluctuating access provisioning, as chronically ill people's abilities (and therefore, access needs) can change drastically over their lives or even over the course of a day. In short, chronically ill people can offer an extreme case study into how the *abilities of an individual* can fluctuate and impact access provisioning.

Many chronically ill people have symptoms that alter their daily lives, and disability activism [Invalid, 2019, Piepzna-Samarasinha, 2018] and academic theorizing [Kafer, 2013, Wendell, 2001, Evans, 2017] are beginning to integrate chronic illness into their approaches. However, despite an active focus on chronic illness in human-computer interaction (HCI) health research (e.g., [MacLeod et al., 2017, Hong et al., 2016, Haldar et al., 2017, Lim et al., 2019]), chronic illness remains conspicuously underrepresented in HCI accessibility work [Mack et al., 2021c] (for a few exceptions, see e.g., [Janicki et al., 2021, Bora et al., 2017, Mack et al., 2021b, Hofmann et al., 2020]). We identify an opportunity for HCI accessibility practitioners to understand the access needs of chronically ill people and to create technology-based solutions that are not rooted in medicalized views of chronic illness.

In this chapter, we articulate an opportunity for future HCI accessibility research to work with and support chronically ill people. To do so, we present three tenets to guide researchers' approaches to chronic illness: 1) move beyond medical framings to understand people with chronic illness as having access needs and valuable expertise, 2) consider that the variability of ability that many chronically ill people experience presents unique accessibility needs, and 3) adopt a theoretical approach to chronic illness that attends to bodily and sociocultural experiences. We then apply these tenets to three autoethnographic case studies about the authors' own experiences with technology use, demonstrating how our tenets can be used to surface design considerations for chronically ill users.

By placing disability studies, HCI, and our lived experience as chronically ill technology users in conversation, we introduce a new paradigm for designing accessible technology. This shift includes viewing access as produced by both a user's innate abilities and the physiological consequences doing an action causes, which we call a consequence-based approach to accessibility. Further, it encourages researchers to consider technology design for community use and alter traditional HCI methods to better match chronically ill participants' access needs. We also emphasize that approaches to technology design for chronically ill people need to be grounded in community knowledge and can be contextualized within disability studies and activism.

In summary, with respect to designing technology for chronically ill people, we contribute 1) three core tenets to guide research, 2) a in-depth authethnographic exploration of how these tenets reveal opportunities to understand and design technology for chronically ill people, and 3) considerations for HCI accessibility practice when engaging chronically ill people.

To this dissertation, this chapter names and contributes a key factor that can fluctuate and impact access provisioning: a person's individual abilities. People with chronic illnesses often experience wide variations in their abilities which impact how the engage with assistive technologies. This factor is the first of several that I identify throughout this dissertation that have implications for how assistive technology can be effectively designed to meet access needs as the context a person operates in changes. Further, this chapter presents autoethnographic accounts of how abilities can fluctuate for people with chronic illnesses. My contribution of these real world examples of fluctuating individual abilities can help technology designers better understand their end users, and therefore design more effective technologies.

3.2 Background and Related Work

To contextualize our work, we situate our definition of chronic illness, explore how HCI has approached work with chronically ill people, and introduce guiding concepts from disability studies.

3.2.1 What We Mean by Chronic Illness

In this chapter, we draw on work from disability studies scholarship to broadly define a chronically ill person as one who has a condition that: impacts functioning, is not expected to go away or be immediately fatal, may be ameliorated through treatment and, particularly when left untreated, can be life-limiting [Crow, 1996, Wendell, 2013, Patsavas, 2014, Price, 2015, Reynolds, 2017, Goering, 2015]. Conversations around chronic illness and disability often overlap - indeed many people identify as both chronically ill and disabled [Pinder, 1996]. While we do not intend to take on questions of chronic illness or disability identity formation, this overlap guides us to engage with disability studies as a source of useful guiding theory and to see chronic illness as relevant to HCI accessibility work. However, we also highlight areas where chronically ill people's experiences diverge from mainstream conceptualizations of disability [Pinder, 1996], motivating the need for a chronic illness specific approach to technology design. Billions of people globally are diagnosed with at least one chronic health condition [Boersma et al., 2020, Hajat and Stein, 2018] (a growing group in the wake of COVID-19 [Taquet et al., 2021]), leading to a wide range of experiences and varied identification with chronic illness. We, however, are primarily interested in how shared functional aspects of chronic illness could be better considered within accessibility. While our framework may resonate more strongly with people who identify as chronically ill, it may also be relevant to many others.

3.2.2 Chronic Illness and HCI

Chronic illness has received uneven attention across subfields of HCI - it is a significant topic in HCI health and online communities research but is scarcely engaged in accessibility contexts. Specifically, the primary foci of current HCI health work on chronic illness include: exploring the different information needs and practices of patients and providers [Berry et al., 2019, Duckert and Barkhuus, 2022, Lim et al., 2019, O'Kane and Mentis, 2012, Salamah et al., 2021, Schroeder et al., 2017, Sun et al., 2013], how people talk to their support networks [Barbarin et al., 2015, Berry et al., 2017, MacLeod et al., 2017, Milewski and Parra, 2011, Pang et al., 2013] how to support pediatric patients, their parents, and providers in effective communication [Haldar et al., 2017, Hong et al., 2020, Hong et al., 2018, Hong et al., 2016, Hourcade et al., 2012, Kaziunas et al., 2017], and how patients gain the knowledge to manage their conditions [Burgess et al., 2019, Chaudhry et al., 2016, Huh and Ackerman, 2012, Pollack et al., 2016, Whitman et al., 2021]. This body of work considers chronically ill people in relation to the medical care they pursue, often primarily referring to them as 'patients', and therefore proposes technology solutions within this medical context. An additional focus of HCI work with chronically ill people is self-tracking, developing tools to track symptoms [Kelley et al., 2017, Mishra et al., 2019, Pichon et al., 2021], treatments [Bassilious et al., 2012, Cantor, 2018, Yun and Arriaga, 2013], and medically-necessary lifestyle changes [Luo et al., 2019, Siek et al., 2006]. This work often includes medical professionals and is geared toward helping patients comply with prescribed treatment. Another avenue of HCI research with chronically ill people outside of accessibility frameworks focuses on how chronically ill people connect with and support others via social media communities [Farnham et al., 2002, Isika et al., 2020, Liu et al., 2013, MacLeod et al., 2015, Mankoff et al., 2011, Sannon et al., 2019, Vlahovic et al., 2014, Zhou et al., 2014, Eschler and Pratt, 2017]. This body of research considers and offers solutions for many areas where chronically ill people can be better supported when seeking medical care, but rarely centers access needs that are not immediately connected to the clinic, like accommodations for work or social life.

There is a small, but growing body of work that situates chronic illness in relation to accessibility and the broader disability community. ASSETS has not historically published much work that engages chronic illness - only a small set of papers include participants with chronic illnesses, often focusing on older adults or rehabilitative technologies (e.g., [Baecker et al., 2014, Bhachu et al., 2008, Chen et al., 2021a, Chen et al., 2021b, Karanam et al., 2017, Nunes et al., 2012, Yu et al., 2014, Zhu et al., 2016]). Some ASSETS publications have considered chronically ill people as having access needs, exploring how people negotiate access at work [Mack et al., 2021b], considering how to make disability activism accessible to chronically ill people [Bora et al., 2017], and centering chronic illness in theorizing around the role disability studies ought to play in future HCI accessibility research [Hofmann et al., 2020, Mankoff et al., 2010]. Outside of ASSETS, HCI work that considers chronic illness within the contexts of disability and accessibility remains sparse. Research on disability-related activist movements has included chronically ill people's perspectives [Auxier et al., 2019, Li et al., 2018], recent conference workshops on accessibility research have explicitly considered chronic illness [Bandukda et al., 2021, Spiel et al., 2020], and researchers have considered the particular access needs of chronically ill people on dating apps [Porter et al., 2017], in the workplace [Ganesh and Lazar, 2021], during research studies [Mack et al., 2022a] and in public places [Janicki et al., 2021]. Considering the prevalence of chronic illness, this body of work is notably underdeveloped relative to other foci of accessibility research [Mack et al., 2021c, Wolters, 2019]. Though this handful of papers examine the access needs of chronically ill people in specific contexts, no work yet theorizes about the broader design considerations needed to make technology for this group. We seek to grow this body of work by articulating a set of tenets to guide future accessibility research with chronically ill people.

3.2.3 Core Concepts from Disability Studies

One of disability studies' central pursuits is to name and analyze the effects of two dominant frameworks for understanding disability: the social and medical models [Oliver, 2013]. The medical model of disability characterizes deviation from physical and/or intellectual norms as undesirable defects that medical intervention can eliminate, augment, or cure, motivated by the belief that a better future is one without disability [Shakespeare et al., 2006, Cobley, 2018]. The classical counterpoint to the medical model is the social model of disability, which names disability as a natural and vibrant part of human diversity and as a basis for historic and current systemic oppression. Rather than focusing on cure, proponents of the social model call for changes to external factors that produce disability (e.g., buildings without ramps, discriminatory policies) [Shakespeare et al., 2006, Oliver, 2013]. Notably, early disability studies scholarship, which articulated the social and medical models, did not center chronic illness in its analysis. Initial adherents of the social model drew a distinction between impairments (i.e., differences in functioning) and disability (i.e., context-specific and social dynamics that create barriers for participation by differently functioning individuals) to help combat what Joel Reynolds calls the *"the ablest conflation"* of the concept of disability with *"pain, suffering, hardship, disadvantage, morbidity, and mortality"* [Reynolds, 2017].

3.2.4 Positionality

This work was deeply influenced by authors' experience with chronic illness, interactions with medical systems, and (for some) moving through the world with a non-normatively functioning body. Three of the four authors identify as chronically ill and all identify as white, cisgender, women.

3.3 Design Tenets for Creating Technology For People with Chronic Illnesses

We present three tenets which outline necessary perspectives to shape technology design for people with chronic illnesses. First, technology designers must view people with chronic illnesses as having access needs and valuable expertise rather than only as patients. Second, chronic illness causes high variability in ability, which is crucial to consider when designing technology to meet chronically ill people's access needs. Third, this work must be done using a model of disability that accounts for both physical and mental experiences of impairment while also recognizing disabling socio-political factors.

3.3.1 Tenet 1: Beyond Patients

We must view people with chronic illnesses as more than medical patients, but rather people with valuable expertise and non-medical access needs.

Much of the existing body of HCI scholarship around chronic illness adopts a health, rather than accessibility, framework (see 3.2.2). Under a medical lens, chronically ill people are primarily viewed as patients with technology needs defined by medical care and symptom management. However, we call for HCI practitioners to contest the dominance of medicalization and emphasis on patienthood when designing technology for people with chronic illnesses. Longstanding critique by feminist [Boston Women's Health Book Collective, 1973, Lorde, 1980], and queer [ACT UP Advisory Committee of the People with AIDS, 1983] activists calls attention to the ways that labelling people as "patients" takes away their agency and imposes a set of assumptions around what patients ought to want, do, and need. The label "patient" also establishes a clear power hierarchy, implying a subordinate relationship to a more knowledgeable and powerful clinician [Edwards, 2014]. Viewing people with chronic illnesses primarily as patients suggests that they can be best understood in a medical context and situates them as recipients and dependents of medical practitioners' expertise. On the other hand, approaching people with chronic illnesses with an accessibility lens views them as people with access needs and creates room to center individuals' agency and knowledge, countering epistemic violence [Ymous et al., 2020].

A medical, patient-centric approach often obscures the deeply contentious relationship many people with chronic illnesses have with the medical field. While medical treatments, testing, and guidance can be critical to chronically ill people's quality of life, the medical field is often simultaneously hostile to chronically ill people [Benness, 2020a, Haagaard, 2022, Haagaard, 2019]. For example, it frequently takes years to get formal diagnoses for many chronic illnesses [Edwards, 2014], patients are routinely not believed by medical professionals [McManimen et al., 2019, Latifi, 2021, Moore, 2019], and complex medical care is often prohibitively expensive [Hayes and Gillian, 2020, Gavin, 2017]. These experiences are exacerbated when people with chronic illnesses are otherwise marginalized because medical racism, sexism, anti-queerness, ableism, classism, fatphobia, and other biases harm people's ability to access care and be treated with dignity [O'Hara and Taylor, 2018, Washington, 2006, Janz, 2019, Cottom, 2019]. Future HCI work must understand that while medical care and assessment is crucial for many chronically ill people, it can also be a primary site of trauma, discrimination, and disbelief. Discussion of and engagement with medical systems must be done with caution and recognize this fraught history. This motivates our focus on non-medical access needs that remain under-considered within HCI research.

At the same time, the knowledge shared outside of medical contexts makes clear that, individually and in community, chronically ill people hold vast expertise derived from both their embodied experiences and navigating the world with a chronic illness. Diagnosis-specific and general chronic illness social media communities are abundant (e.g., [Benness, 2020b, Sannon et al., 2019, Eschler and Pratt, 2017]), and they provide a place to share in-depth knowledge about living with a chronic illness. While much discussion centers on how to live with and acquire care for illness (e.g., symptom and flare identification and management, possible diagnoses, how to navigate the medical system), people also share information and advice to meet non-medical access needs (e.g., developing horizontal workstations, suggesting how to disclose access needs on a date, preparing meals that don't trigger dietary restrictions) [Benness, 2020b]. Indeed, there are myriad individual and group examples that demonstrate the sophistication of this expertise, including a recent reconsideration of graded exercise therapy as a standard of care for myalgic encephalitis/chronic fatigue syndrome (ME/CFS) after ME/CFS advocacy groups demonstrated that it is a harmful practice [Torjesen, 2020, BBC, 2021]. HCI researchers should value this individual and community-based knowledge.

To conduct HCI accessibility work on chronic illness, researchers must go beyond patient framings to view chronically ill people as having access needs and valuable expertise to shape accessible technology design work. This view challenges the assumption that medical providers should always be consulted as subject matter experts, while firmly centering chronically ill people as the relevant, necessary experts that can guide the development of accessible technology. This reframing is also necessary to re-render HCI accessibility work as relevant to chronically ill people. If researchers perceive chronically ill people as primarily patients, primarily medical technologies emerge as relevant supports. However, if we view chronically ill people as having a wide range of access needs that are not well-met in their daily lives, HCI practitioners are well-positioned to create non-medical tools to improve accessibility. For example, access-need driven HCI work with chronically ill people may explore how technology could adapt to a user's varied cognitive abilities, develop research practices that better support someone with fluctuating capacities, and examine how existing accessible technologies could be customized to meet chronically ill users' needs.

3.3.2 Tenet 2: Variability of Ability

The experience of chronic illness is diverse and inconsistent, even for an individual from day to day; consequently, we have to view access not only in terms of capability to complete an action, but also in terms of its repercussions (e.g., consequences such as worsening symptoms).

Chronic illness often causes varying levels of ability, affecting how chronically ill people move about the world, including what technology they use. When people's bodies have vastly different abilities over time, it takes creativity and planning to go about everyday life [Benness, 2019, Piepzna-Samarasinha, 2018, Novak and Benness, 2020, E. and Benness, 2020]. For example, someone with fluctuating fatigue may use mobility or other technology aids some days or times in the day, but not others [Benness, 2019, Novak and Benness, 2020]. Like other disabilities, chronically ill people's abilities and access needs vary between people. However, what is especially critical in examining the experience of chronic illness is understanding the variability of abilities within an individual. We break down this phenomenon by, first, categorizing factors that determine (and vary) ability into two main categories: individual baseline fluctuations and action-determined variability. Then, we propose a view of accessibility that is key for designing technology for people with fluctuating abilities: designing for the consequences of actions rather than solely for static capabilities.

Individual Baseline Variability. Beyond interpersonal variation in experience with chronic illnesses, a single individual can experience internal fluctuations in ability. Many people's chronic illness experiences include "flares", or an overall exacerbation of symptoms for an extended period of time [Mackay, 2019, Berthelot et al., 2012, National MS Society, 2022, Wyant, 2018]. These flares, as well as shorter periods of fluctuation (e.g., a bad symptom day) can be triggered by unknown or hard-to-control circumstances [Wyant, 2018, Milligan, 2022, Bernhard, 2019, Haagaard, 2019]. For example, environmental factors (e.g., a heat wave, pollen, pollution/smog, season changes) or other physical experiences (catching the flu, menstruation) can trigger an overall higher level of disruptive symptoms and, consequently, a lower level of capability to perform daily tasks [Wyant, 2018, Milligan, 2022, Eileen, 2020, Miller et al., 2021a]. These baseline fluctuations can occur rapidly, and therefore technology that is designed for people with chronic illnesses must be usable at a variety of ability levels to meet the user's current access needs.

Action-determined variability. A chronically ill person's ability levels frequently change after performing actions. While arguably, every person enters a different state after performing an action (e.g., after a run, a person might feel more tired) this difference in abilities/state can be extreme for people with chronic illnesses (e.g., post-exertion malaise). For example, a person without a chronic illness might take a shower and detect no noticeable difference in state. On the other hand, the challenges of showering with a chronic illness are thoroughly discussed (and even meme'd) among chronic illness communities because they often result in extreme fatigue, overall malaise, or other symptoms [Grey, 2017, Ayn, 2018, Wyant, 2019]. Since actions may trigger lasting, negative symptoms, this can result in a cumulative effect that leaves chronically ill people with disruptive symptoms and a low capacity to perform tasks by the end of a day. Therefore, technology design needs to consider not just the abilities a person begins with, but the abilities they might have after performing an action, with or without technological support.

The effects of variability: designing for consequences. Because significant fluctuations of ability pervade many chronically ill people's lives, they often have to map out their days based on the expected consequences of each action they plan to take [Miserandino, 2003]. A common metaphor used within the chronic illness community for this form of variable consequence management is the "Spoon Theory" [Miserandino, 2003, Clinic, 2021]. This metaphor for understanding chronic illness, coined by Christine Miserandino, represents capacity or energy with "spoons" and explains that people have to carefully plan what they spend their spoons on in a day, since they are often in short and inconsistent supply; because of *baseline variations*, like a flare, the amount of spoons you can spend in a day may be different on Monday than Tuesday [Miserandino, 2003]. Due to the variety in abilities and symptoms an individual can experience, the number of spoons an action takes cannot be perfectly estimated. Even for the same person, the impact of the same action can vary drastically from 10 AM to 10 PM, though the consequences they incur for that action may be perpetually higher than they are for non-chronically ill people. In deciding how to allocate spoons, chronically ill people perform a complex cost-benefit analysis, informed by the time they've spent living with a condition, to predict the likely costs (e.g., symptoms) of performing a task compared to the benefits they will receive. Therefore, we argue that to understand accessibility in the context of chronic illness, we must account for the consequences an action causes. Under this approach, we frame the accessibility of a task as not solely in terms of an individual's capability to perform a task, but rather the ability to perform a task and remain in an "acceptable" state afterwards.

3.3.3 Tenet 3: Include the Body

Research with people with chronic illnesses must be done using a model of disability that accounts for both the physiological and sociopolitical barriers they face.

Numerous disability studies scholars have explored the ways in which those living in non-normative bodyminds may experience limitations from both physiological impairments and socially constructed dynamics of exclusion [Clare, 2001, Pinder, 1996, Crow, 1996, Wendell, 2013, Patsavas, 2014, Price, 2015, Reynolds, 2017]. In her foundational essay, Susan Wendell argues that for the "unhealthy disabled"—or people who are chronically ill and experience frequent pain, fatigue or other forms of discomfort—a social model view of disability focused on curing ableism disregards a core part of their disability experience. She highlights the fact that many people *"experience physical or psychological burdens that no amount of social justice can eliminate,"* and calls for an approach to disability that does not seek to avoid the realities of physiological impairment [Wendell, 2001]. Motivated by Wendell, we argue that researchers must move beyond the currently discussed social and medical models of disability toward an approach that attends to both embodied and sociopolitical aspects of chronic illness.

Disability scholars have critiqued the social model [Shakespeare et al., 2006, Shakespeare, 2013, Haagaard, 2022] and developed new ways of thinking about disability that center the interplay between individual experiences of impairment and broader society and disability politics. For example, the political/relational model proposed by Alison Kafer *"neither opposes nor valorizes"* medical care, but makes space for '*'the possibility of simultaneously desiring to be cured of chronic pain and to be identified and allied with disabled people"* [Kafer, 2013]. This model makes space to see chronically ill people as political subjects while not needing to cast aside the bodily realities of impairment that have historically been ignored under social model politics.

Other scholars have explored ways that living with differences in functioning can generate deep, visceral forms of knowledge available only to others who share the same experience. Tobin Siebers explains that embodied knowledge arises when *"situated knowledge adheres in embodiment. The disposition of the body determines perspectives, but it also spices these perspectives with phenomenological knowledge–lifeworld experience–that affects the interpretation of perspective"* [Siebers, 2008]. In essence, knowledge does not solely come from a social location, but from the particular, physical experiences of living in a body. Siebers calls for disability theory that engages embodied expertise, not only as an object of analysis but as a conceptual tool that can strengthen design practices and enrich analytical capacity [Siebers, 2019].

We combine these ideas to articulate a theoretical approach to understanding the experience of people with chronic illnesses. To adopt a more nuanced and comprehensive approach to chronic illness, we believe researchers should center the embodied experiences that often characterize chronic illness. This framing balances the tensions between seeking care for unwanted symptoms and valuing disability as part of human expression. We hope this epistemological shift away from a purely social model approach makes space for HCI accessibility work that can account for people's bodily realities without defaulting to a medicalized approach.

3.4 Case Study Applications of Designing for People with chronic illnesses

In the following section, we present three autoethnographic case studies from two chronically ill authors to show how different types of technology can be used to negotiate access in different social and work scenarios. We then demonstrate how our tenets can make sense of these experiences and, following that analysis, highlight potential directions and considerations for technology development.

3.4.1 Background and Methods

Collaborative Autoethnography

Collaborative autoethnography is a methodological approach using autobiographical data as the subject of ethnographic analysis conducted by a group of researchers [Chang et al., 2016]. Autoethnography is a well-established method among disability studies scholars who have both experienced and studied the social and structural dynamics of chronic illness, disability, or long term pain [Frank, 1993, Zola, 1982, Zola, 1972, Wendell, 2001] and continues to be employed by similarly situated researchers today [Nowakowski, 2016, Richards, 2008, Neville-Jan, 2003]. Conducting autoethnography in collaboration produces rich analyses from multiple 'insiders' perspectives of complex health processes [Norris et al., 2012, Nowakowski and Sumerau, 2019, Walker et al., 2020, Smith-Tran and Hang, 2021, Chang et al., 2016]. Inspired by this history of chronically ill people's engagement with autoethnography, we present three case studies derived from our own autoethnographic reflection. We focus on our own experiences and interactions as two chronically ill people to avoid being extractive of broader communities throughout our cases [Flaherty, 2022].

Background

The first authors, McDonnell and Mack, recognized rich examples in their lives around utilizing technology to navigate their own fluctuating access needs associated with chronic illness symptoms. They therefore chose to employ collaborative autoethnography to critically analyze their everyday experiences and reflect on them as case studies.

McDonnell and Mack started their doctoral studies at the University of Washington in the same year. While they met as colleagues collaborating on accessibility research, the experiences they recount here are primarily shaped by a deep friendship that developed over the course of that collaboration. Mack was diagnosed in 2016 with a chronic illness that results in fluctuating symptoms that include motion sickness in the form of dizziness and nausea that can be triggered by physical movements as well as visual stimuli. She has overall malaise that varies, sometimes feeling perfectly fine, other times feeling ill upon waking up. Although McDonnell has navigated significant dietary restrictions since she was young, her identification with chronic illness shifted in 2019 after what she thought was post-surgical recovery became unexplained symptoms that took years to diagnose. McDonnell's symptoms include unpredictable malaise, an inconsistent ability to be upright and active, brain fog, heat intolerance, and fatigue.

To develop their cases McDonnell and Mack first independently generated a set of scenarios where technology was either inaccessible and/or allowed them to meet their access needs, identifying individual examples and reflecting on instances where they used technology to support each other. They then met and discussed areas of overlap between their scenarios, ultimately selecting three cases for their variance, rich engagement with technology, and interaction between the two authors. Throughout this process they referenced their shared messaging history to provide more details about interactions. The full set of authors reviewed these reflections, probing for more details and explanations when needed. Collectively the authors engaged in iterative discussions and analyses, producing the results presented here.

3.4.2 Case 1: TikTok Sharing and Consumption

Our first case examines Mack and McDonnell collaboratively creating access to social media content that is inaccessible to Mack. Their experience demonstrates a community-based solution to a social (nonmedical) access issue and highlights consequence-based accessibility.

The Scenario

McDonnell is both deeply hooked on the social media platform TikTok and fond of sharing videos that she finds amusing. However, Mack cannot watch all TikToks because shaky camera movement makes her sick. Therefore, when McDonnell wants to share a TikTok with Mack, she pauses to assess how much motion is in it, before copying the link over to Facebook Messenger and writing up a motion description of the video [Race et al., 2021]. Although they have since discussed how to best craft motion descriptions, McDonnell began providing descriptions without prompting when she began sharing TikToks, paralleling how she shares image descriptions of visual memes with a blind friend. This description explains how much motion is in the video and may also include consumption guidelines (e.g., wait until someone says “get my coffee” to look at the video) to make semi-accessible videos watchable or context on why Mack might watch it (e.g., it is one of her interests, or McDonnell thinks it’s hilarious, required viewing). Example motion descriptions McDonnell has shared with Mack are:

> “This seems very up your alley though has a lot of motion. The camera is steady when it’s still but moves side to side to track the dancers (in fits and starts though, like it moves, stays, they move out of frame and it then follows, not continuous tracking), and they’re dancing at a reasonably close zoom so all the spins constitute motion on the screen. I will audio describe and pause for you tomorrow if you want “
>
> “Steady cam tho with a lot of jump cuts- you can look at a still at the start and then away for the rest of the video and get 95% of it”

When Mack gets that message, she reads the motion description and decides if it is something she wants and can afford to watch at that moment. For example, when she receives the first description, Mack decides that since she usually feels best in the morning, she can risk watching this video after she wakes, particularly because she knows she’ll enjoy it. It does make her feel slightly ill. Mack then opens the second video and finds that McDonnell was more cautious than she needed to be, and she was able to watch the TikTok video without triggering symptoms.

Applying the tenets

Whether or not Mack watches a specific video at a given time cannot be determined by either party alone: McDonnell and Mack both provide key information to inform these decisions. This process is deeply interdependent and social in nature.

Because her symptoms fluctuate hourly (Tenet 2), Mack's decision to watch a TikTok at any given time needs to consider several interwoven factors. She essentially performs a risk-assessment where her current symptoms and the described amount of motion determines the risk, the level of novelty of the content determines the potential benefit, and missing events or feeling very ill later in the day determines the potential cost. Mack can make this calculation reasonably accurately, thanks to her expertise derived from years of lived experience around what will and won't trigger her symptoms.

What videos to send and what to describe in these videos is highly situated in understanding how elements of the social environment impact Mack's physical abilities and symptoms (Tenet 3). To make motion descriptions effective, Mack and McDonnell rely on building a shared understanding of Mack's symptoms and how to categorize motion. They work together to define a shared vocabulary to consistently describe elements of the social environment (e.g., what is "unsteady camerawork") so that Mack can best predict her physical response to the stimuli. This process involved demonstrative examples and considerable trial and error; to this day, there are still elements of guessing at what kinds of visual stimuli would be accessible and how to convey risk.

Mack's deep, embodied knowledge and McDonnell's efforts to learn her access needs are crucial to this process (Tenet 1). Mack gained an understanding of how her symptoms change in response to different stimuli over years of self-reflection and trial and error, sometimes accidentally triggering negative symptoms. This self-knowledge is crucial to craft social accommodations. As McDonnell is her only friend who regularly sends motion-described TikToks, it is the only way Mack has to safely access this content – there is no existing external mechanism to learn about the motion stimuli in a TikTok in advance. However, McDonnell is not acting as a visual/motion interpreter for Mack - rather, it is an act of friendship that deeply considers access . In practice, McDonnell develops the knowledge of what to include in motion descriptions from being a curious friend who watches a lot of content with Mack, and also from Mack being very open with sharing her physiological reactions. They rely on access intimacy and interdependence to translate Mack's expertise into a social workflow that meets her access needs.

Potential for Technology Support: Contextual Awareness and Customization

This example highlights opportunities and considerations around how technology could better support people with fluctuating symptoms that can be triggered by external stimuli like motion. First, we found that context (i.e., Mack's current state and her future plans) was critical in determining what content she would consume and when. Therefore, gathering users' contextual information through smart device sensors (e.g., microphones, pulse sensors) or other information logged in personal devices (e.g., calendar events)[1] could be a promising application for future work [Karkar et al., 2017, Schroeder et al., 2018, Cho et al., 2019]. However, Mack's example demonstrates the sophistication of expertise needed to identify a user's current state and predict the impact of content consumption, suggesting that solutions may need to include a human-in-the-loop to ensure that sensed contextual information is adequately interpreted. Finally, Mack's experience of chronic illness is also unique from others, and the heuristics she has for what videos may be accessible are particular to her life and body, indicating that personalization would be key if designing accessible technology for this scenario.

Further, this case raises questions of how one might develop machine learning models to increase access when target users can't label training data and face significant consequences when using inaccurate models. While recent developments in customizable machine learning models (e.g., few-shot learning [Wang et al., 2020]), may seem well-suited to the questions of describing motion stimuli or identifying accessible videos, this example challenges several core machine learning practices. Even few-shot learning requires that users provide a training set and then give feedback to iteratively improve models. For Mack to independently curate a dataset of inaccessible TikToks or types of motion, she would likely have to slowly submit examples of videos that trigger her symptoms throughout daily life or undertake video labeling sessions that are all-but guaranteed to make her sick. An alternative model of data-labeling could explore a communal approach, where others (in this example, McDonnell) could curate a training set for Mack. This is not a panacea, as it takes time, transparency, and trust to train proxy data labelers and adds uncertainty to training data - though McDonnell can often make reasonable calls about what is clearly accessible to Mack, she does not live with Mack's symptoms. Additionally, the process of data labeling may also be

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[1] Note that a heavily sensing-based solution cannot be built without careful consideration for user privacy.

a socially-untenable ask to make of others. Further, assessing model performance and providing feedback to improve a model poses significant risk, as the tolerable error rate is very low. Finally, since Mack's decision to watch or not watch a video depends on many interwoven, nuanced factors, this case raise interesting questions for machine learning around how to collect detailed feedback from a user without burdening them.

3.4.3 Case 2: Hacking Text-to-Speech Technology

We now examine a case around McDonnell and Mack's use of text-to-speech (TTS) technology to improve access during their graduate studies. This common tool had the flexibility required to support two different sets of access needs in performing the same task: allowing McDonnell and Mack to continue reading while symptomatic.

The Scenario

Mack's dizziness varies day to day. She finds that 10 minutes of uninterrupted reading consistently makes her dizzy. Consequently, she started using Text-to-Speech (TTS) technologies to read without triggering dizziness. Sometimes, Mack uses a screen reader as a TTS engine, since it has very fast reading speeds, is easily turned on and off, and doesn't require internet access. However, Mack is not a "traditional" screen reader user: she uses her eyes to identify the paragraph of interest, highlights the text with the mouse, and then activates the screen reader. Other times she uses an online TTS tool, NaturalReader[2], designed for sighted users. Some of the visual interactions are useful to her, such as clicking where in a document to start reading, but she has to turn off others due to her motion sensitivity, such as highlighting each word as it is read. While this tool limits listening speed, it works well on PDFs, which are often not fully screen reader accessible.

Context often determines which tool Mack uses. For example, one day, while attending a meeting, her peer sent an abstract for her to read. Since an abstract is short, she chose to read this with her eyes, and it only made her slightly dizzy. However, she was then asked to review an interview protocol draft. This document spanned multiple pages, and given her existing symptoms Mack chose to consume the content with a screen reader. Since it was a group meeting with multiple people, she

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[2] https://www.naturalreaders.com/online/

pulled out earbuds and put one earbud in, leaving the other ear uncovered to ensure she could still hear her colleagues while listening to the protocol. She felt comfortable using the earbuds without judgment or explanation since the meeting attendees knew about her chronic illness.

Meanwhile, McDonnell does not experience any uptick in symptoms directly related to reading. However, her fluctuating fatigue, malaise, and brain fog can make both the physical effort of sitting upright enough to read a PDF on her computer and the cognitive effort of staying focused on a document prohibitively difficult. When McDonnell mentioned that she was struggling to balance work and fatigue, Mack recommended NaturalReader. Initially McDonnell used this tool sporadically, but eventually it became her default reading method. As someone who is not a skilled screen reader user and can consistently navigate interfaces visually, a TTS tool alone serves as a significant access tool.

Through more consistent use, McDonnell has discovered that she uses the tool differently when she needs to get reading done while feeling so physically unwell that she can't be upright than when symptoms are impacting her ability to sustain focus. For example, McDonnell was taking a graduate seminar, which included dense readings, during an academic term where she was experiencing frequent symptom flares. If she was feeling unable to work from her desk, she would pivot to uploading the week's reading to NaturalReader, putting in her headphones, pressing play, and laying down on the floor or couch to listen. This allowed her to continue working and increased the likelihood that she'd be able to complete other work later in the day. If she was instead trying to complete seminar readings while dealing with brain fog, she would load the reading into NaturalReader and then simultaneously listen to audio output while using the tool's sentence-highlighting feature. Multimodal output and consistent pace allowed her to get through a heavy reading load while brain fog made staying focused on reading difficult.

Applying the Tenets

This case demonstrates ways that Mack and McDonnell address the access needs that arise from their chronic illnesses in nonmedical contexts (Tenet 1). Seeing McDonnell and Mack as having access needs de-medicalizes their issues and allows widely available, nonmedical tools to be a part of the solution. Further, McDonnell learning about NaturalReader from Mack exemplifies the common practice of communities creating and sharing valuable expertise with each other about navigating through all areas of life with a chronic illness [Mankoff et al., 2011, Benness, 2020b, Piepzna-Samarasinha, 2018]. Additionally, McDonnell's case provides insight into how individual expertise of chronically ill people evolves: she learned about her own access needs and how to manage them through months of feeling sick, trying new workflows (i.e., using NaturalReader when she was sick, lying on the floor), and recognizing where else they could be useful in her life (i.e., using NaturalReader as a focusing mechanism). Both experiences exemplify the creative workflows and rich insights that can be generated by disabled or chronically ill people hacking technology [Hamraie and Fritsch, 2019, Spatz, 2015].

Mack and McDonnell use TTS in response to the reality of their varied abilities (Tenet 2), despite neither of them being the "typical" target users of TTS systems (e.g., people who are blind, people with dyslexia or other common print-related disabilities). For Mack, TTS works to prevent and manage symptoms. For McDonnell, TTS is a more accessible option than visual reading when she is symptomatic, though she often reads visually without consequence when she is non-symptomatic. In fact, both authors' experiences highlight an interesting perspective on achieving access for chronically ill people: they both can physically read with their eyes, but find reading with TTS to be more accessible. Therefore, for McDonnell and Mack, oftentimes access is about utilizing modalities that lead to less friction during or after the activity more so than working around an inability to perform an activity.

On top of the physical variability that determines technology use, Mack and McDonnell's social and environmental contexts are also key. By default, Mack prefers to read any text longer than a brief email via TTS as it greatly reduces the risk of long-lasting symptoms. However, social context occasionally causes her to be more willing to risk reading with her eyes than to take on the social stigma of using headphones during a meeting. When working with established colleagues who understand her chronic illness, Mack's use of TTS and headphones is unremarkable, but when meeting new collaborators she risks seeming unprofessional or having to disclose full details of her disability to do so. Additionally, McDonnell's use of TTS is highly shaped by her environment - she is far less likely to work from the floor, requiring TTS, when in the office, but will readily do so in her apartment. Both internal and external context are key determiners of what technology support is most useful at a given time.

This case highlights the importance of viewing disability from both a social and physical lens (Tenet 3). For both Mack and McDonnell, TTS meets access needs that are not fundamentally social in nature - they are seeking ways to limit or live with physiological symptoms. This is different from many social model approaches to accessibility which seek to identify and change discriminatory social and environmental factors. However, it is also not a medical model approach - TTS use is by no means a cure or treatment for underlying symptoms, nor does it seek to normalize them to a nondisabled ideal. Further, having access to TTS does, in many ways, meet Mack and McDonnell's access needs in that it allows them to continue their work where chronic illness may have otherwise prevented it. However, they do not reach some ideal state where they are no longer experiencing disability or impairment when these access needs are met - in fact TTS is often most necessary when they are especially symptomatic. By recognizing the social factors at play while also leaving space for physiological experiences of symptoms, we can better understand the goals of these chronically ill technology users and the role HCI technologies can play in achieving them.

Potential for Technology Support: Broader User Bases and Contexts

The fact that McDonnell and Mack are not the "traditional" users of TTS technology raises interesting design questions around how to describe, and market to, technology users. Often in accessibility research, "people who are blind" and "people who use screen readers" are used synonymously. This case is a demonstrative example: not all screen reader users are blind or have low vision. When narrowly conceiving of who the users of accessible technologies are, this purportedly inclusive design ends up excluding people with chronic illnesses and anyone else who designers failed to imagine might have a use for an accessible technology. Categorizations around who is the "intended user" for a technology can lead to increased resistance from institutions (e.g., insurance companies), social stigma, and even denials of requests (e.g., people with fatigue who can physically walk face resistance requesting wheelchairs [Benness, 2019]). Chronically ill people's access needs often overlap with those that are more comprehensively understood by accessibility practitioners, but a lack of attention to chronic illness within the field means that these unique use cases are not considered in design. Future work in HCI accessibility should consider the multiplicity of ways people could meet the same access need and the multiplicity of access needs that can be met by the same technology, moving towards future tools with a wide range of customizable options.

Looking beyond the individual, the broader social and physical environments affect technology use, and therefore need to be considered in when and how to adapt technology for chronically ill people. Bennett et al. proposed a model of interdependence for viewing a disabled persons' interactions with their environment and assistive technologies where technology use is influenced by factors outside of the disabled person and their technology [Bennett et al., 2018]. In this case, we see examples where social dynamics and the need to disclose and explain her disability affected Mack's choice to use screen readers. In other cases, technology supports may become less critical when a trusted ally can provide the same care.

Finally, this case, mirroring trends in online chronic illness forums [Benness, 2020b, MacLeod et al., 2015], demonstrates the crucial role that shared expertise in managing illness has in communities. McDonnell started imagining the ways TTS technologies could benefit her after watching Mack adapt screen reader technologies to her own needs. Since then, McDonnell and Mack have recommended the technology to numerous other people who find benefits in consuming content auditorily. This discovery process could be an area to engage occupational therapists, who frequently focus on creative way to use existing tools to support people in expanding function [Hofmann et al., 2019], though we note that occupational therapy is often not offered or available to many chronically ill people. Future access technologies might consider 1) how they market their capabilities and customizability, and 2) how to share settings so that current users could introduce others with similar access needs to their use of a tool. This feature could reduce the onboarding and learning cost, especially among people with less comfort using new technologies.

3.4.4 Case 3: Remote work

Finally, we explore the ways that remote access allows McDonnell and Mack to more easily meet access needs that emerge throughout their days. This case highlights the importance of viewing some access barriers and remedies as social and others as based in the body (Tenet 3), and it introduces the idea of *internal access conflicts*.

The Scenario

For both Mack and McDonnell, attending meetings and classes virtually allow them to more easily and effectively manage symptoms and participate in otherwise physically-inaccessible events. Both experience symptoms that can be triggered by activity, such as walking or commuting to campus. Mack finds that she cannot easily attend classes or meetings in the morning (and sometimes all day) without feeling debilitatingly sick. For McDonnell, the COVID-precipitated shift to work-from-home made it so that she no longer has to leave the house at set times. She prioritizes going on walks or completing errands after her daily obligations are met, thus lowering the cost if activity triggers symptoms. On top of remote work enabling Mack and McDonnell to arrange their days to better control symptoms, it also makes it easier for them to manage symptoms as they arise. Both find that the work of managing symptoms requires myriad resources, meaning that leaving the house may require packing beverages, snacks that meet their dietary restrictions, medication, or mobility aids. Additionally, aspects of their environment can impact symptoms, and when working in shared spaces, having control over temperature or a place to lay down is not guaranteed. Mack and McDonnell do sometimes choose to go into campus when feeling well or to see specific people, but by default choose to work from home.

McDonnell found further benefits from the ability to disguise how sick she was feeling or her access hacks during virtual meetings. Because of video conferencing's limited view, she could discreetly make adaptations that reduced symptoms. For example, during one evening class session, McDonnell was feeling particularly unwell - her temperature was dysregulated and she was experiencing malaise from having been upright all day. She attempted to limit her symptoms by grabbing Gatorade from her fridge and opening the window next to her desk to cool down. McDonnell was also able to recline somewhat by putting her feet on her windowsill and leaning back in her chair while still appearing attentive in class with her camera on. However, as time wore on, she continued to feel worse, so she turned off her camera, grabbed her computer, and finished class while lying on the floor.

Remote work, while still Mack's overall preference, is not a perfect solution. Though remote attendance eliminates the need to walk early in the day and trigger symptoms, the shaky video feeds of her peers or professors can trigger her motion sickness. Unlike consuming TikToks, Mack often needs and is expected to pay attention to visual content in work contexts. Over months of remote work, Mack found a variety of hacks to avoid getting nauseous during video calls. For example, one day, when a meeting attendee started walking around with their laptop, causing significant motion, Mack opened a Notepad window on her computer and positioned it so that it blocked only that person's camera feed. However, later in the meeting when a person was screen sharing graphs she had to examine, they kept scrolling the screen which made Mack acutely nauseous. Since that experience, she often starts meetings by establishing group norms: asking people to share links to documents with her rather than screen sharing and to keep their devices on a stable surface or turn their cameras off if they are moving.

Applying the Tenets

Mack and McDonnell's experiences with remote work demonstrate the need to move beyond traditional models of disability (Tenet 3). While there are some changes to the built environment that could lessen the burden of in-person work for the McDonnell and Mack (e.g., access to a place to lay down as needed), this social model thinking has its limits because it is not solely the built environment that is disabling in their cases. Their access needs arise from their bodies, highlighting that it is critical to include bodily realities of impairment in theoretical approaches to chronic illness. We do not suggest that isolation by way of an inaccessible environment is justifiable for those who are currently prohibited from being able to participate in physical daily life. Instead we consider that sometimes the most accessible or preferable option is to provide the opportunity for multiple environments, rather than one universally accessible space, following Dolmage's invitation to approach the universal design of spaces as *"multiple and in-process"* [Dolmage, 2015].

The variability of McDonnell and Mack's symptoms and abilities requires considerable, burdensome preparation (Tenet 2). While their homes house a variety of tools to prevent or manage symptoms (e.g., food, medication), these supplies are not usually by-default available in all work environments or in transit. Consequently, they pack their bags with potentially helpful or needed supplies when they leave home to prepare for whatever symptoms might arise. While some days the extra preparation might be fully unnecessary, both find the uncomfortable, sometimes life-threatening, consequences of being unprepared outweighs the cost. This cost is not negligible, however. The process of bringing all the tools to feel prepared takes time, adds stress to their days if they forget an item, and adds physical weight to already fatiguing walks. In McDonnell and Mack's cases, the preparation required for the variability of their abilities is not insurmountable, but the ease provided by a way to remotely engage in work is often preferable.

In this case, we see the benefits and effects on the solutions of viewing people with chronic illnesses as having access, rather than solely medical, needs (Tenet 1). If viewing Mack and McDonnell as patients, the most obvious tools to address the inaccessibility they face while working in person are medical treatments. While both Mack and McDonnell are actively pursuing the medical care that may make the broader world easier to navigate, understanding them as people with access needs makes visible ways they can be better supported holistically. Therefore, the affordances provided by remote work (e.g., the ability to go on and off camera or to block nauseating motion) become legible as accommodations.

Potential for Technology Support: Consider Internal Access Conflicts

While prior work has considered access conflicts between disabled people [Mack et al., 2022a, Hofmann et al., 2020, Mack et al., 2021b, Das et al., 2021], this case explores how technology can create *internal access conflicts*, a phenomenon sometimes discussed within chronic illness communities [McDonagh, 2022]. While attending class remotely alleviated early-morning symptoms for Mack, it created a conflict by causing her motion sickness. Particularly in the case of chronic illness, individuals can have different access needs that overlap, conflict and synergize in ways that lead to unique technology use. For example, a technology whose interface is very visual may lessen cognitive load for users but also lessen the ability to use the tool non-visually. Technology designers should consider that users may have internally conflicting access needs and therefore pay attention to implications of all design decisions and maximize opportunities for customization.

3.5 Discussion

We have identified three tenets for future accessibility research with chronically ill people (Beyond Patients, Variability of Ability, Include the Body), and demonstrated the ways that they can highlight new opportunities for technology design throughout our autoethnographic cases. We now discuss additional considerations that follow from our reframing; the need to account for consequence-based accessibility, approaching design for community use, and methodological changes for working with chronically ill people.

3.5.1 Consequence-Based Accessibility

In this chapter, we present a paradigm shift in how we define accessibility based on a more dynamic understanding of access. The traditional, binary approach to technology that cleaves access needs into “I can” versus “I cannot” fails to encompass the fluctuating needs of people with chronic illnesses. People with chronic illnesses can often technically perform an action that is practicably inaccessible to them because inaccessibility can arise from the repercussions of doing that action. To demonstrate this difference: handwritten text might be pervasively inaccessible to a blind person without the support of technology or sighted companions. However, for someone with a chronic illness that impacts digestion (e.g., ulcerative colitis) they can technically eat all foods, but face severe and debilitating reactions to certain foods, rendering those foods practicably inaccessible. We, therefore, present a paradigm of designing for consequence-based accessibility, which encompasses the consequences an action causes, rather than solely the innate in/ability to perform a task.

Viewing technology design through the lens of consequence-based accessibility acknowledges that many chronically ill people have the **choice** to incur consequences, even if those consequences cause discomfort or more access needs. Perhaps Thanksgiving dinner is worth a flare in gastrointestinal symptoms, a cute summer outfit without compression socks may be worth later unsteadiness, and running to catch a kid falling off a playground structure might take precedence over the later malaise these actions could trigger. Chronically ill people learn to live in their bodies, and perform a complex calculus to determine which consequences to avoid and which to weather, shaped by variables such as current symptoms, future plans, environments, urgency, social context, availability of accessible options, resources, desire, and many more.

As designers of accessible technology, we need to reconsider what “accessibility” means to people who have the option to partake in an activity, but with varying costs. While chronically ill people often also deal with more “traditional” access barriers (e.g., low fine motor control in their fingers may make it so they can’t open a jar), other access needs arise when performing an action. When we consider the impact this framing has on technology, we see areas for innovation. First, technology can collect and provide easy access to the information that chronically ill people need to make well-informed decisions (e.g., a snapshot of what they have planned for the day, recent heart rate trends). Providing the right information at apt times poses interesting technical challenges. Second, systems can consider how to best adapt their interfaces and operations to meet their users' needs after an action (within or outside of the system) triggers symptoms. For example, symptomatic users may benefit from a lower-cognition interaction mode or shifting from visual to auditory content output. Future research avenues could focus on learning what these levels of accessible modes of operation are and when to enable them.

To operationalize fluctuating access needs, technology designers must recognize that chronically ill people constantly define and redefine what constitutes "unacceptably impaired," and therefore inaccessibility. Individuals determine what is inaccessible to them at a given time based on deeply personal and contextual factors, performing a situational "consequence calculus" to determine if an activity is worth its consequences. Having the ability to adjust their definition of "accessible" to their current context can afford chronically ill people greater agency, but also introduces internal and external doubt around the validity of people's access needs. In thinking about the technological consequences of redefining accessibility, we see that supporting user agency and contextual adaptations is key.

Finally, approaching accessibility through a consequence-based lens that centers the underrepresented experience of chronically ill people creates potential to better meet the individualized, contextual needs that many disabled people have when using accessible technology [Hurst et al., 2013, Franz et al., 2019]. Future accessibility work done using a consequences-based model could consider that, for example, many blind and low-vision people's vision changes based on the time of the day, or could account for the optical and mental strain that speechreading for long periods of time has on d/Deaf or hard of hearing people, or better match the needs of people with mental health disabilities that are cyclic in nature (e.g., bipolar disorder). Further, we hope that our interrogation of what designers assume when we think about "accessibility" serves as a useful starting place for future researchers to interrogate the paradigms in which we work.

3.5.2 Designing for Communities

Our cases provide examples of two chronically ill people sharing access support (Case 1) and knowledge (Case 2); these themes of using care networks or other chronic illness communities to make sense of one's condition and create access hacks in day-to-day life is documented within HCI (e.g., [Farnham et al., 2002, Isika et al., 2020, Liu et al., 2013, MacLeod et al., 2015, Mankoff et al., 2011, Sannon et al., 2019, Vlahovic et al., 2014, Zhou et al., 2014]) and among disability community activists [Piepzna-Samarasinha, 2018, Piepzna-Samarasinha, 2021, Wong, 2020, Mingus, 2011, Barbarin, 2022]. When working with a group of people who have already built, engaged in, and found joy within [Mingus, 2011] a community, we propose that interdependence may be a more appropriate goal for technology design than independence, following Bennett et al's framework [Bennett et al., 2018]. Indeed, the act of being cared for, like receiving aid from a care network, might provide emotional benefits that outweigh the benefits of independence provided by purely technological solutions.

Designing for interdependence involves building for transparency with others and oftentimes giving other users capacity to take action. For example, consider a system where trusted friends could monitor the biological levels (e.g., heart rate, blood sugar) of a person with a chronic illness and be alerted to intervene or provide more support in symptomatic times. The people given these privileges might be trusted members of care networks. However, we must also resist a naively optimistic view of care, and consider how to build systems in a way that could protect and grant agency to a chronically ill person in an abusive or unsafe care arrangement [Justice, Nd]. Further, though interdependence can take the form of a nondisabled person supporting a disabled person, our case studies and examples from communities (e.g., [Mankoff et al., 2011, Benness, 2020b, Piepzna-Samarasinha, 2018]) demonstrate support maintained fully within chronically ill spheres. Thus, any systems designed to support chronically ill people must avoid assuming a distinction between support giver and support recipient - chronically ill people are often already both.

3.5.3 Doing Research with Chronically Ill People: Effects on Methodology

As we propose an approach to HCI accessibility research with chronically ill people, we also reflect on how research methods may need to change to be accessible to this population. Prior work describes how to plan accessible studies for people with disabilities, including accommodations for varying fatigue or incorporating notions of crip time [Mack et al., 2022a, Lazar et al., 2017, Coyne and Nielsen, 2001]. Mack et al. describe ways to allow for more flexibility like allowing interviews to take place over multiple sessions, building in breaks, and adjusting the space to be comfortable for participants' bodies [Mack et al., 2022a]. Centering a chronically ill perspective, we add allowing access to food and drink, prioritizing remote facilitation options, explicitly providing the option to participate from nontypical locations (e.g., the floor), and considering potential sensory sensitivity triggers (e.g., motion, light, loud noises).

There are other methods which may be challenging to run with strong internal validity while prioritizing participant beneficence. Consider, for example, within-subjects controlled experiments, which rely on the assumption that an individual's capacities are an experimental constant. How might a testing instrument account for the reality that someone may begin a study reporting a 2/10 on a pain scale but end it at an 8/10 (perhaps directly due to their participation in the study)? Further, what is the procedure if a participant with fluctuating symptoms shows up to a study without the access need for which they were recruited (e.g., someone with fluctuating brain fog has no brain fog on the study date)? This perceived "threat" to internal validity may be appeased if symptoms could be triggered consistently, though we argue that this is unreasonable to ask of participants (e.g., triggering a migraine can have hour or day long impacts). One solution may be to perform data collection *in-situ* when the necessary conditions occur naturally rather than engineering a symptom increase; while this may lessen internal validity, it increases ecological validity and prioritizes participant beneficence. In general, we suggest strategies of planning studies that prioritize the access needs and comfort of participants, even if it means being more creative in the study design. Because chronically ill people's access needs often manifest differently than HCI anticipates, researchers must pay careful attention to methodological in/accessibility when working with people with chronic illnesses.

3.6 Limitations and Ethics

Our work has limitations and necessary ethical considerations. First, autoethnographic methods are not designed for broad generalizability, and the examples we provide in this chapter come from the experiences of two people with similar demographic backgrounds. We do not intend our work to serve as a survey of chronic illness experiences, but future research could explore how our tenets operate when applied to a wider range of experiences. At the same time, using autoethnography allowed us (Mack and McDonnell) to reflect deeply on our own relationship with each other and technology in creating access. We argue that this type of reflection would have been much more involved and difficult, if not impossible, to attain through other methods as autoethnography allows access to data that would take hours of interviews and observation to compare to. Additionally, as we outline ways of engaging with a large, broadly defined community, our scope is wide. There are open questions around how chronic illness and other forms of bodymind difference (e.g., mental health disabilities) overlap and diverge, and we encourage future work to explore this nuance. Additionally, we are not able to speak to the wide range of ways that people identify with chronic illness and/or disability, a promising area for future work. Finally, while we believe that HCI accessibility work that includes chronically ill people could serve under-considered populations, we are also cognizant of the harm that technical intervention can cause. We encourage designers and researchers to adopt a critical eye around whether their work is needed and useful, or another disability dongle [Jackson, 2019, Jackson et al., 2022].

3.7 Conclusion

In this work, we present three core tenets for HCI community members to consider when designing technology for people with chronic illnesses. First, we must look beyond patienthood to see chronically ill people as having access needs and expertise. Second, we highlight that variable ability requires us to consider accessibility in terms of the consequences actions cause. Finally, we provide a theoretical approach to chronic illness that highlights both bodily and socioenvironmental factors. We demonstrate the utility of these tenets through the analysis of three autoethnographic reflections on the technology use of two chronically ill authors, noting implications for technology design. Finally, we discuss the implications of consequence-based accessibility and what researchers should consider when designing technology for and conducting research with chronically ill participants. We hope that this work spurs more work in the HCI community that focuses on the access needs of this growing population.

Chapter 4

ANTICIPATE AND ADJUST: CULTIVATING ACCESS IN HUMAN-CENTERED METHODS

This chapter is based on [Mack et al., 2022a] (screen reader accessible).

4.1 Introduction

Work contexts are a meaningful place to study group accessibility as many people work in collaboration with others, which can result in mixed ability teams. In this chapter, we choose to focus on the domain of HCI research. HCI practitioners often facilitate different group events for research, be that interviews with a researcher and a participant (a small group of two) or workshops (a group of tens of people). Regardless of the type of HCI research being performed, there is a possibility that the researcher has a disability or that the participant has a disability. Consequently, this is an ideal context to study the key considerations for creating access for different types of group activities with all disabled or mixed ability groups.

Moreover, besides defining key considerations for general group accessibility, this chapter specifically focuses on making HCI research processes more accessible for both disabled researchers and disabled participants. HCI risks excluding and harming people if methods and studies are crafted without centering the needs of minoritized groups. For example, scholars have critiqued binary gender encodings in surveys [Burtscher and Spiel, 2020, D'Ignazio and Klein, 2020, Spiel et al., 2019b], white and wealth supremacy embedded in participatory design [Harrington et al., 2019], and the erasure of disabled voices in HCI research [Ymous et al., 2020]. Specifically, disability scholars raised awareness of historic and ongoing violence done to disabled people who have been nonconsensually subjected to research or who are regularly recruited without receiving credit or benefit from the research outcomes [Beecher, 2001, Faden and Beauchamp, 1986, Iacono and Carling-Jenkins, 2012, Ymous et al., 2020]. Prior work documented the inaccessibility built into everything from the cultures and norms of academic institutions to the tools that are popular or well-supported [Dolmage, 2017, Jain et al., 2020, Shinohara et al., 2020, Shinohara et al., 2021, Ymous et al., 2020], showing that fields with low representation of the communities they aim to serve are especially likely to make such mistakes. Increasing the representation of disabled people in academia is nontrivial when systemic barriers to access pervade the institution.

In this chapter, we investigate the accessibility of human-subject methods for both disabled participants and for study facilitators with disabilities. We consider not only the activities involved in running a study with participants, but the accessibility of the full method pipeline, from selecting a method through analyzing and summarizing data. Consequently, we interviewed 17 accessibility experts about their practices. Participant's backgrounds included accessibility and disability research and organizing in greater disability communities outside of academia. We invited community organizers in addition to formally-trained researchers, because disability scholarship and activism contend that disability communities hold significant accessibility expertise [Dolmage, 2017, Invalid, 2019]. All interviewees worked to make activities which are associated with HCI methods accessible, such as workshops, interviews, and usability studies methods. However, while our recruitment centered accessibility experts, we argue that our contributions are crucial for all HCI researchers (beyond those studying accessibility) to cultivate inviting spaces for disabled people's perspectives.

Through these interviews, we find that creating access was a careful labor which spanned every phase of the research process, from choosing methods, to running studies, to writing papers. Analyzing examples across interviewees, we define four dimensions of projects that were key to establishing an atmosphere of inclusion: communication, materials, space, and time. We additionally identify a broader trend of anticipating access needs while simultaneously adopting a flexible mindset that allows for making adjustments on-the-fly. Further, as power hierarchies impacted the everyday planning and execution of interviewees' research studies and events, we highlight how power influences how access was handled (e.g., negotiations between researcher and participant or junior and senior team members). In considering these tensions, we finally contribute strategies for planning accessible research studies, which we built into a workflow (see Figure 4.2).

To this dissertation, this chapter contributes an overarching framework of "anticipate and adjust:" an approach to addressing access needs where one anticipates what accommodations might be needed, and then adjusts to meet what the person with a disability needs in-the-moment. Throughout the next chapters, I conduct empirical research with disabled technology users. In analysing the data from their lived experiences, I identify different factors that fluctuated and impacted access provisioning in group contexts. By compiling this list of factors, I provide technology designers with a resource to better **anticipate** how end-users' technology usage scenarios may change, thereby allowing them to **adjust** how their technologies function to best meet access needs in-the-moment.

4.2 Related Work

HCI has embraced a variety of methods [Lazar et al., 2017, Olson and Kellogg, 2014], and literature reviews have enumerated their use [Koeman, 2020]. For example, recent studies recruiting people with disabilities commonly leveraged interviews, usability tests, and controlled experiments mack2021we. But for a few exceptions (e.g., [Lazar et al., 2017]), formal training in this wide variety of method is rarely concerned with how to conduct accessible studies. Further, these instructions tend to assume participants, not researchers, have disabilities. In our review of prior work, we highlight what is documented about the use of accessible methods in user research and then situate these considerations in wider conversations on disability and academia.

4.2.1 On method accessibility

Little research focuses on the accessibility of methods, and research methods are rarely taught to be conducted accessibly, as evidenced by few focused textbooks. Two exceptions include a chapter by Lazar, Feng, and Hochheiser [Lazar et al., 2017] and a report published by the Nielsen Norman group [Coyne and Nielsen, 2001]. These both focus on accessibility in user-centered research and highlight how considerations span the research process. For example, Coyne and Nielsen documented their considerations and adaptations from recruitment, to consent processes, to payment [Coyne and Nielsen, 2001]. Turning to research, a few works focus on accessibility considerations in working with people with a specific set of abilities [Dickinson et al., 2007, Scott-Barrett et al., 2019, Spiel et al., 2019a]. Many other accessibility papers surface anecdotal information about method accessibility which typically addresses only participants in the study at hand, and thus lack generalizability (e.g., [Kane et al., 2012, Potluri et al., 2021]). This body of work primarily focuses on specific, highly-contextualized methodological changes, summarized below. We also overview literature regarding higher-level considerations around who has access needs and how varied power dynamics and abilities among stakeholders shape inclusion.

Adapting Methods to Increase Accessibility

Scholars have made several communication adjustments to make their studies more accessible [Dickinson et al., 2007, Frauenberger et al., 2016, Frauenberger et al., 2017, Galliers et al., 2012, Johansson et al., 2015, Kane and Galbraith, 2013, Kane et al., 2012, Scott-Barrett et al., 2019, Valencia et al., 2021, Williams and Gilbert, 2019a]. For example, some work encouraged researchers to consider how people may contribute in nondominant ways (e.g. nonspeech options during real-time interactions [Galliers et al., 2012, Kane et al., 2012]). Additionally, researchers have offered multi-modal communication by, for example, supplementing real-time instructions with visual aids [Galliers et al., 2012, Johansson et al., 2015, Kane et al., 2012, Williams and Gilbert, 2019a]. Other work emphasized recognizing different paces of participant communication. Beresford in Scott-Barret et al. employed an 8-second rule in their research with Autistic individuals to insert pauses for thinking [Scott-Barrett et al., 2019], and Johansson et al. scheduled discussions to occur over several sessions while working with participants with mental health and cognitive disabilities [Johansson et al., 2015]. These scholars recognized that they could not always predict how people will best communicate, so they offered multiple options and slowed the study pace to honor various contributions [Dindar et al., 2017].

Researchers also considered how participants would interact with prototypes or other materials in studies. Due to the inaccessibility of many professional tools (e.g., high-fidelity prototyping [Li et al., 2021], CAD [Hofmann et al., 2016, Siu et al., 2019]), they turned to physical, lightweight prototyping mediums, like using wood and fabric to design circuits [Jelen et al., 2019] or other materials such as foam, Legos, Play Dough, and Wiki Stix for general design tasks [Jelen et al., 2019, Potluri et al., 2021]. Other times, visual-dominant, paper-based prototyping activities (e.g., brainstorming) were eschewed for more multimodal, rich methods of engagement (e.g., bodystorming) [Metatla et al., 2015, Metatla and Cullen, 2018]. Often with common craft supplies, these researchers have opened up design activities to wider audiences of people with disabilities. However, there is still no roadmap for developing such solutions in diverse contexts, especially those with participants with different disabilities.

4.2.2 Disability and Academia

Research cannot be divorced from the environment in which it is performed. Often, in academia, ableist perspectives inaccurately signal that disabled people cannot do research [Ymous et al., 2020]. In particular: "[we think of] disability as a problem in need of a solution" and not as an "important form of critical knowledge production within the university" [Dolmage, 2017]. These assumptions are built into norms and tools, requiring disabled people to develop creative work arounds and spend extra time accomplishing the same tasks as nondisabled colleagues. For example, to work around barriers presented by popular collaborative writing platforms like Google Docs, blind and low vision academics had to create custom workflows to comment on each other's content [Das et al., 2019]. Similarly, high fidelity prototyping tools useful in producing study materials render inaccessible outputs [Li et al., 2021]. In other cases, disabled researchers chose not to participate in certain research activities (e.g., using maker spaces) or social activities (e.g., networking at conferences) because of their inaccessibility [Yıldız and Subasi, 2020]. Finally, certain artifacts (such as data visualizations) which are crucial to communicating research are pervasively inaccessible [Sharif et al., 2021].

To combat the normative assumptions engrained in academia, disabled people adjust workflows to succeed, and document the ableism that they often face along the way. Jain et al. detailed how the three authors with distinct disabilities found accessible workflows in graduate school, demonstrating that formal systems for accommodations are not always effective, naming them "misaccommodations" [Jain et al., 2020], and Chua highlighted the need for frequent accommodations updates [Chua et al., 2017]. Shinohara et al. found similar trends, which they refered to as "inequitable access" [Shinohara et al., 2020]. Even if a student had formal accommodations, they were often insufficient, necessitating what Jain et al. called "uncharted accommodations" [Jain et al., 2020]. For example, existing accommodations did not support d/Deaf or hard of hearing (DHH) or blind students in interjecting in conversation, so, Jain and Potluri passed a pillow to both visually and nonvisually facilitate turn taking during meetings. Shinohara et al. relatedly pointed out the "access differential" experienced by disabled graduate students, since there are clear differences in time and effort between those who need to perform access labor, like scheduling interpreters, and those who do not [Shinohara et al., 2020].

As we recount access labor associated with executing methods, it is important to consider this broader ecosystem in which the work is conducted, which includes spending extra time and effort creating accessible alternatives and pushing against ableist attitudes in academia. Further, documenting how to perform accessible work that counteracts systemic barriers, like that offered in this paper, may increase adoption of such methods.

4.3 Methods

We conducted semi-structured interviews with 17 US- and Canada-based accessibility experts. To generate inclusion criteria that could span academic and organizing work, we used popular resources [Lazar et al., 2017, Olson and Kellogg, 2014, Digital.gov, nd] to create a list of 17 activities that fit the scope of our inquiry, such as conducting experiments, usability evaluations, interviews, workshops, design or fabrication activities, and quantitative and qualitative analysis. Upon receiving institutional review board approval, we released a screener survey which requested that respondents share brief examples of how they have made qualifying or related activities accessible for any stakeholder (e.g., themselves, other researchers, collaborators, or participants). We recognized that ableism systematically impacts people with non-normative bodyminds[1] whether they identify as disabled or not. Therefore, our recruitment also invited participation from those with experiences related to chronic illness and other health conditions, neurodivergence, those who are DHH, and those otherwise systematically marginalized by academic research[2]. Accordingly, on the screener survey we also asked prospective participants to optionally self-identify their gender, race, disabilities, and access needs for an interview.

When enrolling interviewees, we actively selected for a diverse group in terms of activities conducted, disability communities of focus, and other demographics. Interviewees had between 2 and 15 years of experience (median 5 years) conducting qualifying activities. Other self-reported aggregated demographic information is presented in Table 4.1.

Interviews were up to 90-minutes long and were conducted via a video calling platform. At least

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[1] According to Sins Invalid: “The relationship between the human body and mind as a single integrated entity ... [which] affirms the reality that our minds and bodies cannot be separated” [Invalid, 2019].

[2] We consulted with participants on their preferred higher-level terms (e.g., disabled, Autistic) and use this language when describing and individual interviewee. Occasionally, we abstracted disability labels to preserve anonymity (e.g. chronic illness instead of specific diagnosis).

Table 4.1: Participants' self-reported disability identity, race, and gender, along with their role and the types of activities that they performed.

Role		**Self-reported disability identity**		**Self-reported race**	
Community Org.	4	Autism	2	Asian	5
Researcher	13	Blind or visual impairment	2	Black	2
		Chronic illness/medical condition	5	Chicano	1
Activity types		d/Deaf or hard of hearing	3	South Asian	1
Fabrication	4	Developmental disability	1	White	8
In-person group activities	11	Learning disability	3		
Interviews	12	Mental health disability	6	**Self-reported gender**	
Remote studies	12	Motor disability	3	Cisgender man	5
Surveys	7	Multiple disabilities	7	Cisgender woman	9
User research	3	Nondisabled	3	Female	3
User testing	6				

two co-authors attended each interview, with one author acting as the primary interviewer and the other(s) asking follow up questions and supporting as needed. Audio and video of these sessions were recorded and transcribed for analysis. Finally, participants were sent a paper draft, a summary of the findings, and a list of all of their quotes and examples for review. At this point, they could request for their chosen pseudonym or real name to be used in the chapter; real names are denoted with an asterisk (*). Participants were compensated $50.

Our semi-structured protocol asked interviewees to first overview their experiences which qualified them for the study. We then asked them to share examples of making qualifying activities accessible from the recent past, and to share other poignant examples of accessibility successes and challenges. While listening to these examples, the interviewer asked follow-up questions to learn the roles and responsibilities of everyone involved, associated access needs, and the various attempts made to meet them, whether they ultimately worked or not. Interviewers concluded by asking interviewees to identify patterns related to (in)accessibility of the various activities they facilitated and to share desired changes which may address them.

4.3.1 Data Analysis

Six authors analyzed the interview transcripts, which followed a thematic coding process [Braun and Clarke, 2019, Braun and Clarke, 2006]. These authors each read a subset of transcripts to develop an initial codebook. They iterated on the codes through discussions over multiple meetings until reaching coverage and consensus. Examples of the near 60 codes included ableism, space, and adjusting communication. All transcripts were analyzed by two researchers- the initial coder segmented and coded the transcript, and the second coder then reviewed those codes, suggesting additions and questioning unclear codes. The two researchers who had coded each transcript then met to resolve any differences they found. Mack was the first coder on half of the transcripts and the second coder on the other half to ensure consistency. After the data was coded and discussed, we created the higher-level themes presented below.

4.3.2 Accessibility Considerations

We anticipated that our participants would have access needs, and therefore asked interviewees to optionally make access requests in the screener survey and during interview scheduling. Needs we fulfilled included using interviewees' video calling platform of choice and hiring interpreters. We also designed the interview process to be accessible for ourselves, as a team with several disabled researchers. We discussed and agreed upon accessible tools and practices, such as meeting norms (reading chat messages out loud and intentional turn-taking), written documentation (Google Docs and Microsoft Word), and an accessible data analysis strategy (detailed below).

However, as we conducted the study, we incorporated more accessibility considerations. Some of these were learned from participants and provided during subsequent interviews. For example, one participant frequently asked us to repeat questions, so we offered to share the interview protocol in advance with subsequent interviewees. We additionally began offering breaks to everyone after an interviewee, Heather*, shared that she gave her participants breaks during long study sessions. However, some adjustments were made on-the-fly. For example, Mack was not feeling well on the day of one study and coordinated a plan to switch roles, if needed, with McDonnell; the two decided to do so for the last half hour of that interview. At the beginning of another session, we learned the interviewee, Jae*, was nonspeaking. Bennett, the blind lead interviewer, received consent from Jae* for another researcher present, Mack, to re-voice Jae*'s typed chat messages and gestures; interviews were collaborative processes where interviewee and researcher accessibility was co-created.

Furthermore, our data analysis process was affected by our own access needs. Since some analysts used screen readers, we chose not to use a qualitative tool like Nvivo or Dedoose, which are inaccessible. We instead opted to code in spreadsheets and developed a screen reader-accessible annotation system, before considering how visually accessible or intuitive it was for team members who did not use screen readers. While these disclosures may not always be safe or possible, we are opting for transparency to model methods reporting that may help readers replicate similar studies accessibly and to communicate how access remained central throughout our process.

During our interviews, we quickly learned that accessibility was more than a short list of provisions. Rather, to determine the best approaches to meet access needs, our interviewees thoroughly considered the people involved and the steps required to plan and execute activities. We first present unique facets of access work associated with different phases of a research process, from methods selection to analyzing data. Additionally, across activities, we drew out key meta categories of access provision (communication, materials, time, and space) which we elucidate in subsection 4.4.2. We conclude with unique interactions and tensions presented by interviewees' mixed ability teams, drawing out access synergies, conflicts, and power relations. Overall, our findings offer insight into the specific and careful work of making activities popular in HCI research methods accessible.

4.4 Findings

Note that we use "interviewee" to refer to the 17 people enrolled in our study and "participant" to refer to subjects in interviewees' studies or attendees of interviewees' events. We additionally use the term "facilitators" to refer to our interviewees performing their roles as researchers or organizers.

4.4.1 Accessibility Throughout the Research Process

Interviewees shared a core belief that it is important to include people with disabilities in research and to ensure that they are treated respectfully, responding to the fact that academia and its institutions are built on a history of both excluding and exploiting people with disabilities. One interviewee, Dhruv, expressed that accessibility is increasingly a buzzword, a “sexy little thing” that people use to bolster resumes. Interviewees emphasized that instead, true commitment meant that all phases of studies needed to be accessible. Michele* positioned accessibility as a shift in mindset that altered her entire research process:

> “We don’t think [of disability as] diversity. [But] how we view disability impacts every other aspect of how we go about anything [in research] ... So if you’re not constantly thinking about accessibility, ... it’s very easy to ... only think about people who don’t have disabilities.”

In line with Michele*’s assertion, we summarize the measures that interviewees took to build access for themselves, their collaborators, and their participants across multiple stages of research and community organizing. An example from each stage is shown in Table 4.2. We include both participant and facilitator considerations, when applicable, in each subsection, as we are committed to not assuming facilitators are nondisabled.

Table 4.2: For each stage of the research process, we present an example quote from participants, along with which of the four dimensions of Communication, Materials, Space, and Time the example incorporates.

Stage	**Dimension**	**Participant**	**Quote**
Doing your homework	NA	Amy	“Before I reached out to my participants ... I scheduled a meeting with someone I know ... who is an expert [researcher] in this field and who has interviewed with neurodivergent people before. ... I was reading in particular the methods section of previous papers that included interviews with neurodivergent people ... [and] things that they have done.”

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Table 4.2 – continued from previous page

Stage	Dimension	Participant	Quote
Method selection	Time	Heather*	“[For] most of the individuals I interviewed, fatigue or cognitive or physical stamina was also a concern for them, which made me think: well then, this needs to be done in installments or segments.”
Recruitment	Communication	Angel	“On all my recruitment letters I have my phone number So if they are more comfortable with calling, which a lot really were, they would just call me to ask more about the study and we’d go from there.”
Initial conversation around access needs	Communication	Amy	“[I talked to a participant about their access needs before the interview] and they were very clear that I needed to use the live captioning and Google Meet; [its] captioning was better. So I used Google Meet and I used another screen recording software on my local machine to record the conversation. It was a little difficult from my research perspective, [but] I really wanted to make it accessible, which meant [if] it was a little bit difficult on my end ... [like] finding a new screen recording software, [that was okay].”

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Table 4.2 – continued from previous page

Stage	**Dimension**	**Participant**	**Quote**
Transportation	Space	Michele*	"So I ended up finding another location that had a conference room that we could get; I think [it was] reasonably priced... [and it] met the criteria of: accessible from [the] Metro and easy for me to meet them in the lobby."
Preparing the space	Space	Alex	"As a matter of respect [for Deaf culture] and equitable access, voicing was not allowed in the lab. People who had to take phone calls had to leave the space."
Obtaining consent	Communication & Materials	Alex	"[For our consent forms,] we have English [at grade] 10 [reading level] or below because some of our ... Deaf participants, their first language is sign language and it's not English. So, [we use] simple direct English ... They read that and then ... if they don't understand a question, we're able to sign the form to them to give more accessibility to the questions that they're answering."

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Table 4.2 – continued from previous page

Stage	Dimension	Participant	Quote
Running the study	Materials	Hazel	“[For a prototype in the study,] we had a few different demos with different modalities so that they would be accessible. So one of them made a lamp turn on and change colors. One of them played a piano noise and one of them started a phone call on my phone. We wanted something visual and something auditory and then my phone would vibrate. So if someone could not see or was both blind and deaf they could hold it and physically feel it vibrate. We wanted to make sure that there was a variety there.”
Data analysis and writing	Time & Materials	Dhruv	“So everything that I’ve kind of done around the data collection and data analysis process is automated. So from the time that the data is collected it’s just plugged into an R script and that produces a spreadsheet on Google docs. so that saves me a lot of clicks [which are fatiguing]”.
Member checking	Communication	Sarah	“I would send them the paper once it was accepted. I would send them any notifications of awards I got for the papers. I also sent them every single paper I produced for my thesis in what I called a more accessible blog post. so I would include things like visuals, like my slides that I ended up presenting, where I would summarize the paper. I would give them ways to get in touch with me. They also all got copies of their transcripts so they could redact anything.”

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Table 4.2 – continued from previous page

Stage	Dimension	Participant	Quote
Reflection	Communication & Materials	Angel	”For instance, one of my first interviews with a [participant], she received the interview transcript ahead of time. These are things that I didn’t actually solicit for feedback, but I was totally open to it. And at the end of the study she was like, ‘you know, it would be best if you change some of these terminologies.”’

Doing your Homework

When starting a project, interviewees first took the time to learn the basics about a community of interest and how to accommodate them. Sometimes interviewees had a head start when they worked with people whose access needs they shared. For example, Heather* and Dhruv frequently experience fatigue and that shaped the pacing and length of their studies. However, regardless of disability status, all interviewees emphasized the importance of continued learning with humility. Interviewees found this learning not only important for their own education but to recognize the work others, particularly people with disabilities, had trailblazed before them; *“I was like: holy shit, there are people with checklists out here”* (Heather*). They pointed to disability scholars’ and activists’ books and blogs which have curated ample guides for conducting accessible events, which may be adapted to fit specific research contexts [Bennett et al., 2019, DO-IT, 2015, Invalid, 2019, Kushalnagar and Vogler, 2020, Roper et al., 2018, SIGACCESS, ndb, SIGACCESS, nda, Unger et al., 2021]. Indeed, for readers who are new to accessibility work, we recommend acquiring a baseline of knowledge through resources that cover more structural concepts than this chapter; see: [Invalid, 2019, Lazar et al., 2017]. Through a variety of means, interviewees allocated time to learn about their communities of focus and how to best support them in studies.

Method Selection

Interviewees' professional training heavily influenced their methodological choices; they consequently adapted specific methods to be accessible rather than avoid them. For example, Christina*, who is blind, approached running diary studies, which are typically highly visual, by asking blind and low vision participants to create entries with text and voice memos, simultaneously increasing access for participants and herself. Similarly, Dhruv conducted a controlled experiment with people with motor impairments and had to restructure his experimental design from within-subjects to between-subjects. This decision increased the minimum number of participants needed, and added a new confound, participant dexterity. But, between-subjects was considered an acceptable tradeoff, as it decreased the total time and effort required of each participant while preserving quantitative rigor. With creative adaptations, interviewees could almost always make the methods accessible that best met project goals.

Recruitment

After defining a study, interviewees worked to make sure their recruitment materials were accessible, considering both the file format and the recruitment message. Interviewees prepared recruitment fliers suitable for text messages, phone calls, or online disbursement, choosing the mediums popular among those they sought to recruit. Making the language clear and understandable was a priority for several interviewees; Alex, Zack*, and Jae* all created flyers which kept language at or below a certain reading level (e.g., 4th grade). Further, Alex, Yuzu, and Daniel* translated materials into their communities' native languages. In some cases, this labor was extensive and inaccessible. For example, Daniel* recruited nondisabled volunteers to assist in translating documents from English to Spanish, to work around the suboptimal performance of his screen reader in Spanish and the inaccessibility of free language translation tools.

The language used in recruitment materials was crafted carefully to reach diverse and qualified participants. Hazel reflected on this process of crafting recruitment language:

> " everyone I've worked with identifies as disabled or as comfortable with that language. but I really want to capture ... that broader experience and people who are living with some kind of impairment, or a medical condition that they don't identify as a disability."

Hazel uses identity-first language as a disabled person, but she also recognized that using stigmatized terms might exclude some qualified people from participating. Language not only defined bounds of who could participate, but also who felt like they belonged in the target group. Sarah recounted prioritizing recruiting a diverse sample receiving treatment for a serious illness. She adapted her recruitment message:

> “My recruiting language was attracting people ... who were fairly privileged ... And I changed my recruiting language ... I said I want to hear from you ... particularly if you weren’t happy with your care. And that’s when I start getting queer participants, participants of color, participants who had [multiple] disabilities.”

Interviewees learned that their initial recruiting language often reached a narrow, more privileged subset of the population and they pulled on deep background knowledge (e.g., on disparities in healthcare) to signal their awareness. Importantly, Sarah had acquired this background knowledge through years of experience in the area, which was an important precursor to adjusting her recruitment messaging.

Initial Conversations Around Access Needs

Before a study began, interviewees almost always had a conversation around access needs with participants in their preferred communication medium. An important aspect of this simple, but critical conversation was ensuring that its scope exceeds the disability of interest for the current study. Occasionally, interviewees learned that their protocol was inaccessible for someone with multiple disabilities, and they adjusted their recruiting language to exclude such participants. However, Christina* took a different approach. She prepared for blind participants, and when she learned an incoming participant also had a cognitive disability, she edited the tasks as she learned the participant’s abilities. Christina* recounted,

> “They wanted to participate because they wanted to have their voice heard, but they couldn’t complete the task. So I tried to ad hoc gather information from them. That was still very useful ... but it wasn’t under the parameters of the research questions.”

Christina* decided facilitating accessible participation was more important than running that study session consistent to others, and as a result, her team benefited from learning that person's under-recruited perspective. While studies must maintain a certain scope, which may require ability-related inclusion criteria, in retrospect, researchers emphasized the need to plan for how to incorporate people with multiple disabilities, who are often left out of research and can provide crucial feedback [Hofmann et al., 2020, Mack et al., 2021c].

These access needs conversations were also held among research team members to adjust study planning, execution, and data analysis for disabled researchers. However, some disabled interviewees explained that they only felt comfortable disclosing such needs or disabilities in supportive environments. For example, Shoshana contrasted the atmosphere created by her supportive supervisor with a less-connected group: *"I got weird vibes in the second team and ... [I'm hesitant to disclose] especially when I am in a research setting where I don't know people who would step in, in case something ableist or dismissive happens."* In that case, Shoshana presented access needs as "preferences" so she could avoid disclosing her disability. Some interviewees had accumulated experiences of their access needs being disrespected, so while access needs conversations often normalized adjustments, they also concerned arranging protection by accepting team members and strategically framing needs requests.

Transportation

Interviewees recognized that traveling and navigating outside of well-known routes can be an effortful task for people with disabilities. Consequently, interviewees evaluated potential study locations for the accessible space they offered and their proximity to accessible routes, including public transportation (Michele* and Hazel) or nearby parking (Hazel and Jae*). In some cases, interviewees facilitated activities that involved movement by gathering accessible route maps and offering transportation choices. For example, during one project, Kayla* conducted a multi-day activity and used incline-annotated maps and wheelchair accessible vans to allow attendees to assess their mobility and symptoms each day, and to then choose their preferred transportation. However, planning did not end at the bus stop or parking lot. Interviewees recognized that, especially in laboratory studies, it might be nontrivial to navigate to the correct building and room. Consequently, Hazel, Christina*, and Angel met their participants close to where they arrived and guided them to the right room. Finally, transportation barriers could be so severe that interviewees decided remote participation was most ethical. For example, Dhruv determined that it was not worth the cost in time, fatigue, and comfort for his participants with motor disabilities to visit the lab; instead, Dhruv adjusted the protocol to allow for remote participation, prioritizing participant comfort over the internal validity benefits of controlling details of a physical study environment.

At the same time, interviewees considered their own access needs in choosing locations. For example, Heather*, Hazel, and Dhruv offered to travel to participants to conduct studies, but had to consider if the suggested location was reachable via modes of transportation that worked for their needs (e.g., accessible buses). In sum, regardless of the method used, transportation to the study site and the location within a site was a key consideration.

Preparing the Space

Preparing and selecting the physical space to conduct a study was a detailed process, which we discuss further in Section 4.2.3. Spaces had to meet the access needs of both the researcher and participant. For example, Heather* often opted to let participants choose a location they knew to complete the study, which was more likely to be accessible for them. However, she also had to consider her heat intolerance:

> "One [participant] who uses a power chair [said]: 'I love this place down the street ... they've got a great outdoor patio,' and it was July. And I was like 'yeah that's not going to work for me unless you want to meet there about 6:00 AM [when it is cooler].'"

To resolve this researcher-participant access conflict, the two found a nearby location with wheelchair access and air conditioning.

In other cases, interviewees' access needs did not affect the space, and they prepared spaces mainly based on the access needs of their participants. For example, when Hazel worked with people with mobility disabilities, she brought a door stop to ease entry into the room and she removed chairs from the table, allowing participants to choose their preferred spot before selecting her own space. In another example, Zack* and Jae* hosted several events together including conversations, games, and art projects which parallel activities common in design workshops. Their low budget constrained location choices, so they assessed the sensory triggers in the space and circulated a detailed description to their prospective autistic attendees: *"Something like ... 'The event is held in a library room that is ... large. occasionally there's an air conditioner unit that runs and creates ... a banging noise unexpectedly.' "* Providing this description to interested participants helped them decide if and how they could attend the event. Zack* and Jae* discovered during the COVID-19 pandemic that remote events were popular and may be more accessible than physical spaces for some; they were in the process of determining how to maintain a remote participation option as they considered resuming in-person events. Choosing a location can be challenging due to competing priorities (e.g., budget, facilitator and participant access needs), but it was key to setting a tone of respect for participants.

Obtaining Consent

Our interviewees highlighted key considerations toward fostering an accessible consent process including the language of the consent materials, how consent information is presented and approved, and viewing consent as an ongoing process. Similar to recruitment information, some interviewees worked diligently to ensure that their consent forms were accessible to all participants. For example, Lindsay went through a back-and-forth process with her local Institutional Review Board to create a plain language translation[3] of consent materials, which often included both simplified text and images to convey key concepts. Interviewees were similarly flexible with the medium used to convey consent. Several participants accepted consent by voice call or voicemail, and Angel found that some participants did not trust technology and therefore preferred to sign physical consent forms. Christina* went one step further and ensured participant understanding by asking them to explain back the consent information. Finally, Sarah highlighted the need to reaffirm/reconsent throughout the study as participants' abilities and comfort changed (e.g., after receiving strong medication). Positioning consent as a conversation with flexible mediums (e.g., explaining verbally or with American Sign Language (ASL)) fostered a more comfortable atmosphere for participants to question and engage with the process.

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[3] For more information on plain language translation, look at online resources.

Running the Study

Interviewees worked extensively to make their research protocols accessible for themselves and team members. For example, Alex hired interpreters to accommodate hearing team members during a project with Deaf researchers and participants. Other interviewees created accessible versions of materials, such as the braille and electronic versions Christina* used to facilitate card sorting activities, and Heather*'s interview protocols with prompts in large, bold type to reference if she experienced brain fog and needed a guide to keep track of the conversation. Consideration continued to the end of the study session, when interviewees such as Michele* and Christina* helped participants activate their compensation.

Interviewees commonly provided multiple modes of engagement, as participants' preferred medium could be unpredictable and change throughout the study. For example, Hazel conducted a prototyping activity by offering Play-Doh and Wikki Stix, coloring supplies, and assistance; thus, participants could choose how to engage, and she could avoid assuming their preference. Similarly, when discussing the experiences of having a severe illness, Sarah conducted both a verbal interview and sketching activity to allow participants to share things they were uncomfortable or unable to express verbally due to treatment side effects or limited medical vocabulary. Meanwhile, providing more structure was optimal in other cases. For example, Angel acknowledged multiple choice questions can be leading, and thus threaten validity, but she used them to make studies accessible for participants in the later stages of dementia [Kane and Galbraith, 2013]. When accessibility conflicted with standard research methods, interviewees recognized the tradeoffs but worked to prioritized participant access and comfort, which could also increase study sample size and representativeness.

A final consideration concerned access negotiations made within a group of facilitators and participants. Interviewees shared a commitment to accommodate as much as possible, but recognized that sometimes not everyone could be fully accommodated. While Jae* spent significant time searching for accessible locations, and adapting if participants reported inaccessibility, she recognized that sometimes not all access needs could be met in a space. Both she and Zack* described the importance of transparency, by sharing information about features (including inaccessible features) of a space in advance. In another example, Zack* described the different, conflicting access considerations in making a flyer:

> “It’s also kind of a fine line between ... explaining things in plain language [and] making sure it doesn’t sound patronizing. Cause a lot of folks with disabilities hate being talked to like children and sometimes plain language can sound like that.”

What was an accommodation for one participant might be belittling to another. Zack* had not found a solution. He opted to keep materials in plain language but he spent time reflecting on how potential language may impact him as an Autistic person and trying to ensure the messages also sounded professional. While participant had different, sometimes conflicting, access needs, they could often be accommodated with multi-modal engagements and negotiations amongst facilitators and participants.

Data Analysis and Writing

Data analysis and writing workflows used by teams including people with disabilities were almost always influenced by the accessibility of common tools. Regarding data analysis, Hazel discussed the inaccessibility of qualitative coding software for her blind co-author, which they addressed with a spreadsheet-based workflow. Other common tools for designing prototypes mentioned included Miro and Figma, which were inaccessible both to people who were blind or low vision (Christina*) [Li et al., 2021] and people who had motor impairments or disabilities that affected memory and processing (Sarah). Regarding quantitative analysis, Christina* consulted her blind community to learn which tools (e.g., R, SPSS) were accessible with screen readers and Dhruv, who is easily fatigued, created his own scripts so that he could run his statistical analysis at the press of a button, saving him time and energy. As is studied in prior work [Das et al., 2019, Jain et al., 2020], developing collaborative writing workflows which are also accessible and equitable remains challenging. Overall, we found that the “default” tools, either defined by institutional subscriptions or organizational norms, were often inaccessible, and therefore disabled interviewees took on an access differential by exploring tools beforehand [Shinohara et al., 2020].

Member Checking

Several interviewees discussed their member-checking process, which involved sending interview transcripts, final papers, or presentation materials to participants for their approval and critique.

Lindsay's motivation echoed other interviewees, *"Having done a two-hour interview with someone, I am not the expert of their experience..."* However, reading several pages of an unedited interview transcript was inaccessible to her participants with cognitive impairments. So, she presented interviewees with their data along with summaries of the major themes to validate her ideas with them. While member checking is assumed to function as a mechanism for granting participants greater power, Lindsay's experience demonstrated that this attempt at power redistribution was not automatic. She had to adapt raw data to be accessible, and this work created a tension with minimizing researcher power in the interpretation process.

Reflection

Finally, interviewees emphasized how meeting access needs was always a learning experience. They were vulnerable in sharing that they made mistakes along the way, and acknowledged the role that their participants played in their own growth. Angel, Heather*, and Hazel all recounted stories where their participants were experts and taught them how to improve their interactions. However, not all mistakes were resolved through amicable feedback. In one instance, Sarah reflected that she wished she had better prepared more junior team members for studies:

> "[The junior team member said] I don't want to go to people's homes because I'm afraid of being in danger ... At the time I was like, '... yeah, in-home work is not for everyone. You know, it can be intimidating. You may be in an unfamiliar neighborhood.' ... Then at the end of the data collection, [they] said to me: '... none of these people were dangerous. They were just [experiencing disability].' And I was like, oh my God, you thought these people were dangerous."

Throughout her interview, it was clear that Sarah was dedicated to making her participants feel comfortable, and through this experience, learned that an important part of ensuring their respectful treatment is through team disability awareness and dispelling stereotypes. Relatedly, Lindsay commented that she still struggles with knowing how to best train new people in accessibility. She debated over how to allow new facilitators to learn and grow while protecting participants' comfort, which was her highest priority. Learning from participants through feedback or making mistakes was key to interviewees' growth, but they questioned how to support learning without necessarily perpetuating mistakes that can harm participants.

4.4.2 Anticipation with Adjustments

Moving from descriptive to more analytic themes, throughout our interviews, we found patterns in motivations and practices. First, interviewees did as much as possible to anticipate access needs and plan to meet them, and this anticipatory process was considered part of exhibiting baseline professionalism and respect. Simultaneously, they discussed the individual nature of access needs. As studies and events progressed, people learned how to articulate their needs in the specific context, discovered new needs, and adjusted plans. It became clear that accessibility is not something that can be prepared once and then ignored; interviewees' studies and events were unlikely to be fully accessible unless facilitators adjusted each session to each participant and maintained flexibility.

To better describe how interviewees balanced anticipating access needs and adjusting after, we distill dimensions of access. We found that across study phase and stakeholder group, access needs often impacted communication, materials, space, and time. We offer a few examples of each dimension and how each dimension interacted with others.

Communication

Accessibility requires continuous negotiations, and communication is at its root. Interviewees who relied on translation and interpretation to foster accessible communication explained how materials, time, and space were inseparable from ensuring everyone could participate.

Before he could facilitate studies between himself and DHH participants, John often requested captioners and ASL interpreters, which required him to negotiate with supervisors and accommodations administrators at his institution to schedule and pay these professionals. Beyond logistical considerations, John sought providers with whom he had established rapport, as those familiar with his voice and communication style could often more accurately convey his words. Once a study session began, communication concerns shifted to arranging the space and materials, as Figure 2 displays. John elaborated,

> "[At the table,] the participant would sit to the right of me because I am right-handed,

> so I'm more comfortable turning right. And the interpreter would sit to the left of me, in front of the participant. And then there was a caption screen directly in front of me. The captioner would sit on the side of the participant. So, if I [also] wanted to interact with the captioner I could do that."

To further aid in communication, John used an iPad which displayed the current question so that participants could easily read the correct prompt if there was confusion in ASL interpreting or captioning. Even then, communication breakdowns could occur and John learned to implement a "conversation reset," pausing for 10 seconds to allow himself, participants, interpreters, and captioners to take a beat before resuming the study (similar to [Scott-Barrett et al., 2019]). Even with John's extensive planning, the optics of the space could change in a moment. He explained, *"I would be fine, but in the middle of the interview, the cloud would go away and then magically, the sun would appear. And then the sun would reflect on the tablet and the caption screen, and I couldn't see anything."* John would then rearrange the seating configuration to account for the environmental change. Interviewees negotiated access through diverse, continuous communication channels that ranged from reaching up the ladders of their institutions for necessary resources like captioners, to seconds-long readjustments to ensure everyone processed the last captioned phrase.

Materials

Materials facilitated multimodal communication, sharing, and creativity. From papers, to iPads, to arts and crafts supplies, to furniture, they offered seemingly infinite reconfigurations and reimaginations of access. During one fabrication study Hazel offered ample materials which would aid in visual and tactile self-expression. But as materials accumulated, they posed challenges around space – Hazel and her co-facilitator with motor disabilities could not easily transport them, so she researched whether she could borrow a cart from her institution's facilities department. Finding that there was no clear institutional channel for such requests, she reconfigured available materials by tying teammates' office chairs together to roll materials from her lab to the study room.

Further, materials were an integral part of defining the quality of interaction. In this same study, Hazel created demos of the fully fabricated, interactive prototype where the device produced lights, sounds, and vibration to ensure all participants had an engaging, accessible reference. Similarly,

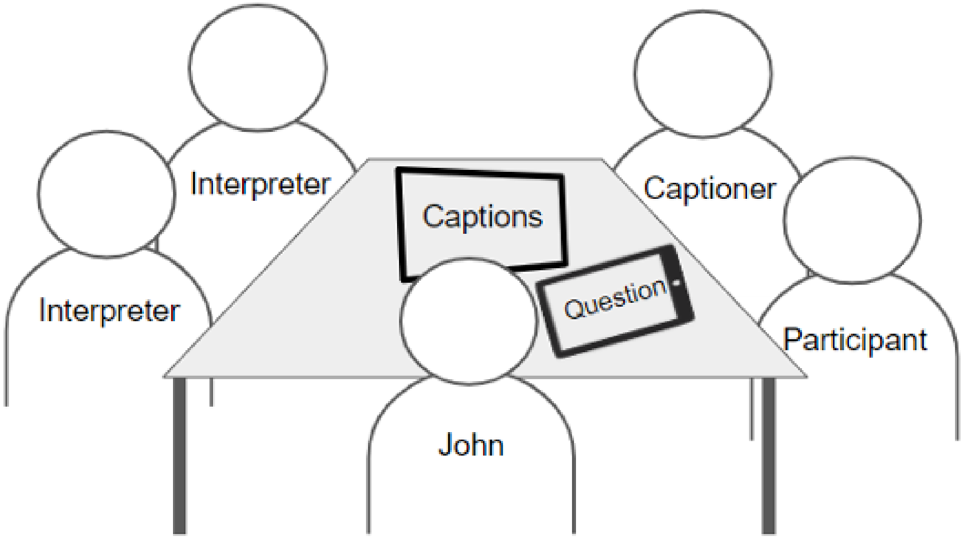

Figure 4.1: A diagram of John's setup when interviewing DHH participants. John thoughtfully organized the space to ensure sightlines between himself and his captioner, himself and the participant, his participant and the interpreters, and himself and his participant to the tablet with interview questions. This diagram was created and shared with John's permission and feedback.

Daniel* passed around objects shown in presentation images so blind participants could directly interact with them,

> “We were able to take slates and styluses[4], Dymo tape[5] ... it wouldn’t have been very accessible had we shown up and given just a verbal presentation, it really helped us having the items to share to the room so they could look at it, touch it, use it.”

In these examples, accessibility went beyond ensuring one could consume content passively (such as through describing an image), by adding multimodal interactivity to foster understanding and reciprocation.

Space

Space accessibility was crucial for conducting studies. It not only served a practical purpose of allowing people to gather and complete tasks, it also communicated expectations about who could be there, what could be done, and how people would be treated. Communication was crucial in making space; Zack*’s messages about sensory expectations and potential triggers helped participants to prepare to be in the space, and to choose a remote meeting when necessary. In contrast, while working in hospitals Sarah had no ability to control the space in advance. Thus, she planned to rearrange space as needed upon arrival. Based on prior experience and education, she understood that hospital rooms are intimate spaces, often serving as residences, but also ones in which a patient’s personal space is frequently invaded. Therefore, she began studies by asking about personal space and boundaries in hopes of maintaining what she called, “the harmony of the room”; she explained: “A lot of time there’s no seating for another person ... or the space for seating is for the family. And so as a researcher, you have to think about: how am I taking up space here? Am I blocking the entry for healthcare professionals?” Sarah sat next to patients, taking care to not lean over them due to her prior infantilizing experiences when she was a patient. She also had to be prepared to move quickly and/or end the study early when a participant’s healthcare needs and medical provider and family visits took precedence. In another example, Alex reflected on the differences between conducting

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[4] A slate and stylus can be used to write in braille.

[5] Dymotape is adhesive tape that can be embossed with braille.

research in in-person DeafSpace[6] [Edwards and Harold, 2014, Gallaudet University, nd] and online. While his in-person working environment was both designed to enhance ASL comprehension (e.g., good lighting, open spaces) and set Deaf cultural norms as the default, this did not transfer to online videoconferencing platforms. Attendees needed more reminding of best practices and that moving online made enforcing some cultural norms infeasible (e.g., hearing beginner signers would default to using chat or captioning rather than immersing themselves in the new language). Sarah and Alex demonstrated the role accessible space played in facilitating comfortable interactions, and how communication, materials, (such as rearranging furniture), and taking time to reestablish protocols (such as cultivating DeafSpace virtually) aided in creating and maintaining harmonious spaces.

Time

Interviewees recognized that disabled stakeholders (e.g., themselves, participants, collaborators), may have different relationships with time than research norms assume, which drove both planning and flexibility. Communicating about time became particularly important during one of Heather*'s studies, as conducting biographical interviews is lengthy, and she and her participants could not always predict when their symptoms would flare. Heather* could preplan some conditions for their access needs, such as meeting for shorter time blocks over multiple sessions rather than one long session. Other time adjustments were unplanned. Heather* reflected,

> "There were so many interviews that got rescheduled or we got 15 or 20 minutes in, and I would check with a person like, 'how are you doing?' And they'd just be like 'I just want to pass out.' I'd be like 'Easy, done. [Let's postpone.] See you in a week.'"

Other times, Heather* ended interviews earlier than scheduled if she could not work through her symptoms. But in other cases when her brain fog was not as debilitating, she initiated more breaks and relied more on accessible materials such as her large print, paper protocol to aid her memory. Yuzu operated under a different mode of flexible time when running workshops where she used videos to communicate topics with participants. After showing a video once, she offered

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[6] A socio-architectural movement that seeks to shape the built environment to match Deaf cultural norms (e.g., supporting ASL and visual communication).

to rewind it for anyone who wanted to watch it again. Yuzu reflected that because rewinding was a mainstream process, it normalized information review as commonplace, rather than special treatment. Further, this saved her from having to repeat information herself, and allowed participants who did not need to watch again to proceed with their activity. Thus, multiple temporalities were supported while maintaining group cohesion. Conceptualizing time creatively and flexibly, what some disability scholars have called cripping time [Kafer, 2013], helped Heather*, Yuzu, and others to run accessible studies [Dindar et al., 2017, Johansson et al., 2015, Scott-Barrett et al., 2019]. Communication ensured everyone understood time adjustments, and materials supported stopping time (to read a protocol during brain fog) or going back in time (to reinforce learning) as needed.

4.4.3 Impacts of Disabled Researchers

Some unique qualities and interactions emerged within teams with disabled, DHH, neurodiverse, and/or chronically ill members, which our 14 interviewees who identified as such distilled for us. We discuss 1) the unique skills that disabled researchers contributed to a team, 2) how teams changed their workflows and processes to accommodate access needs, and 3) situations where researcher and participant access needs intersected in unexpected ways.

Utilizing Knowledge from Lived Experiences

Disabled researchers applied the embodied knowledge they learned about disability throughout their lives to improve their work with participants. In instances where facilitator and participant disabilities overlapped, interviewees built and piloted studies using their own abilities as a baseline. For example, Dhruv conducted a study with people with mobility disabilities where fatigue was a concern given the tasks at hand. Dhruv first piloted the studies himself:

> “I tested it out a few times and at a few times of my day when I had the most fatigue to see ‘what is the cap?’ But then when the participant came in it was a much lesser time than that ... [It was] based on my access needs first then refined by the access needs of our participants.”

Next, Zack* was conscious to not patronize participants with plain language so he used his own experience as an Autistic person as a litmus test: “If something’s pissing me off based on the way

I wrote it then I'm sure others will have the same experiences as well. So it's thinking 'would this feel patronizing if this was sent to me?"' In these examples, interviewees established some access baseline by leveraging the deep, rich knowledge of their own lived experience to anticipate participants' access needs.

Interviewees also described an intangible aspect of working with disabled participants that was not shared by their nondisabled colleagues; there was a sense of access intimacy [Mingus, 2017] due to shared experiences of living a disabled life. Hazel explained how she creatively self-disclosed her disability during a fabrication study:

> "[As a demo] we [engaged] my [access technology] to show people I am also a disabled person. We did that partially to just make people feel more comfortable ... people just look at me and I am disabled and they know that this is a safe space or that I get it."

Hazel showing her access technology was a signifier of shared experiences and this disclosure led some participants to feel more comfortable, and to then be more open. Heather* described a similar fast connection over shared needs when interviewing other disabled or chronically ill people:

> "I would always say, 'by the way, I've got a bladder the size of a walnut. So probably about every 20 minutes I'm going to ask if we can take a quick bio break' and folks would laugh but I found that it usually wasn't just me. There was often a sense of shared intimacy around taking quick breaks."

In this scenario, Heather* used humor and vulnerability to share her access needs, and the light-hearted communication established that it was also ok for participants to share their needs. However, Heather* explained a downside to establishing a shared set of common experiences: *"[Participants] were very quick to revert to 'I don't need to tell you because [long pause],' and I'd be like, 'no, really, that's why we're here. Please tell me!"'* Heather* had to consciously prompt for more details when participants assumed she knew what they were talking about due to shared backgrounds and experiences. When our interviewees brought their lived experiences of disability into the work they conducted, they found that not only could they smoothly prepare to work with people with similar disabilities but that there was a unique form of knowledge generated through shared identity, and they had to be intentional to ensure that participants shared this explicitly rather than assuming mutual understanding.

Negotiating Access Needs

When people with disabilities take on facilitator roles (e.g., researchers), their access needs must be incorporated into a process and space that often assumes their absence. Consequently, teams of facilitators negotiated creative workflows to ensure the access needs of disabled members were met. Additionally, as our interviewees specifically worked with disabled communities, participants often had their own access needs which could interact with those of the facilitator, requiring them to negotiate both access needs and power dynamics.

Our interviewees who were members of larger teams often discussed the process of dividing up who performed what work, considering access needs in this process. In access need negotiations, disabled researchers reached out to their other colleagues and resources in their environments to develop interdependent workarounds. For example, Christina*, a blind person, leaned on sighted colleagues for assistance locating participants in a large lobby; then, while working with a colleague with motor impairments, she took more initiative to do tasks, like developing presentation scripts, that required more keyboard use. Kayla*, who runs programs with the help of several disabled and nondisabled colleagues, mentioned that negotiations are not solely focused on access, they are about making sure everyone on the team is satisfied: “workplace accommodations doesn’t [just] have to be [about] disability ... [we] integrate it in with: how can we all be more successful?” Accessibility provided scaffolding to open communication on Kayla*’s team so others with needs, such as childcare, could express them and adjust their work responsibilities accordingly. However, sometimes access needs could not be considered equally with others. For example, Hazel commented that she preferred qualitative coding and writing tools which were inaccessible for her blind collaborator, so they chose screen reader accessible alternatives:

> “It didn’t make sense to press the need to change the technology that [collaborator] was used to ... I just had a personal preference - no real benefit to it. If there had been a real conflict in terms of using that technology or if I had some benefit I think there would have been more of a conversation of how to compromise.”

In these situations, researchers embraced interdependence [Mingus, 2017] to facilitate accessible studies and events and in doing so they had to weigh tensions and preferences. In some cases, the tradeoffs were minimal. However, when tradeoffs impacted participation, collaborators resorted to equitable distribution of labor by for example, accepting an inconvenient workflow to avoid someone being completely excluded.

Finally, situations arose when facilitators and their participants had to negotiate access needs, since often both parties were disabled. While power dynamics arise among colleagues, they are pronounced between those in facilitation or research roles and those in participant roles. In some cases, disabled interviewees felt tension while attempting to balance their own access needs, participant access needs, and organizations' expectations around project timelines. John mentioned almost always having a conversation around how to arrange access support personnel at a table, but reflected that: *"There have also been times when [my participant] knew a particular set up that they wanted but it was not accessible for me. And then, you know, who do we prioritize then?"* In the end, John and his participants were able to come to a resolution that satisfied both parties' access needs, but the negotiations have left him wondering what to do when solutions may not be easy. Additionally, Zack* expressed his own worries around not being able to meet his participants access needs for frequent, multimodal reminders and sensory information transparency while also not burning himself out:

> "One thing I have struggled with is because of my own executive functioning difficulties– sometimes it might take me longer to get the flyers out than I would want. And I sometimes worry that people wouldn't have enough time to request those accommodations."

John and Zack* articulated difficulty in balancing meeting their needs as people in power facilitating research studies and events, respectively. They did not want to dismiss participant needs but they also were unsure when it was appropriate to prioritize their own. Interviewees could provide examples but struggled to advise how to smooth out potential power-laden conflicts, highlighting a gap in research training on how to handle both power and oneself with care.

4.5 Discussion

Making human-centered methods accessible is labor that takes careful consideration and iteration. Existing research, particularly in the field of accessibility, focuses on how methods can be adapted to support disabled participant access in specific contexts and for groups with similar disabilities [Dickinson et al., 2007, Kane et al., 2012, Potluri et al., 2021, Scott-Barrett et al., 2019, Spiel et al., 2019a]. We complemented and expanded this prior work by analyzing the access work of 13 researchers and 4 community organizers, 14 of whom have disabilities themselves. We identified a guiding principle of "anticipating with adjustments" that spanned four particular dimensions of studies: communication, materials, space, and time. Beyond a checklist or logistical concerns, we drew out specifics of this labor, some of which was informed by the unique, embodied experiences of disabled facilitators. Above, we discussed how multiple stakeholders in the research process negotiate access, and below, we introduce an access workflow to scaffold supporting disabled researchers and participants at each stage of the research process. We argue that these considerations are paramount to uphold the humanity in our field's namesake.

4.5.1 Acknowledging and Teaching Access Labor

The access labor put into making methods accessible often goes unmentioned in academia, contributing to its broader invisibility [Branham and Kane, 2015b]. Methods sections of papers omit access accommodations, as do most research methods classes and textbooks. These omissions increase the risk of harming people with disabilities in research because project facilitators continue to be untrained and under-prepared to run accessible studies, devaluing accessibility as a critical contributor to successful, high-quality research. Additionally, they erase the embodied and crucial labor that disabled facilitators contribute; several interviewees' intimate knowledge about access from personal experiences gave their teams a higher baseline upon which they could develop more meaningful interactions. We discuss each of these premises below and then argue for new norms around training and documentation.

Improperly training facilitators about supporting access risks harming participants. Yet, inexperience with disability was pervasive across interviewee reflections on onboarding new team members. Our interviewees reflected on times where they made mistakes without considerable negative consequences, but other examples, like Sarah's trainee who presumed people with disabilities posed a danger to them, highlighted how easily research encounters could turn harmful [Ymous et al., 2020]. This raises questions around the ethics of onboarding people into accessibility work without training them (e.g., capstone students) to perform complex, accessibility-focused studies, like developing novel access solutions.

Instead, we suggest that initial trainings and research experiences focus on two main areas. First, research training must emphasize gaining a baseline knowledge around disability, and specifically the subpopulation of focus (e.g., Deaf communities). While this training should include learning how to support common access needs of this group, we stress the benefits of also learning about the community and/or culture of the group. Understanding these deeper aspects of groups can exemplify how accessibility knowledge may be implemented, which may ease the "anticipate" process and sensitize researchers to quickly notice when "adjustments" are necessary. Going further, deep, participatory engagement with communities, like Heather* demonstrated in selecting her projects, can lead to better alignment of community and researcher agendas; for more details on connecting with disability communities and creating a more participatory engagement with participants, see these other examples [Frauenberger et al., 2017, Kane et al., 2014, Monteleone, 2018, Spiel et al., 2019a, Valencia et al., 2021, Williams and Gilbert, 2019a].

Second, we suggest that trainings teach researchers to incorporate microethics, or the ethics of small-scale interactions [Spiel et al., 2018], into their regular practice. The framework may guide planning, execution, and reflection from the recruitment messaging to conversations during a workshop. Scholars Brulé and Spiel demonstrated that continual awareness of theirs and others' positions in a research study oriented them to consider complex scenarios laden with power relations and multiple stakeholders having different needs with nuance and care [Brulé and Spiel, 2019]. For example, a microethical framework could reveal and challenge stereotypes that conflate disability with danger while also developing a safety plan for study procedures that include working in unfamiliar spaces. While this brief example is not indicative of what training should look like, it exemplifies one way to incorporate the process and power dynamics of access work into research skill building. Relatedly, Williams and Gilbert discuss the importance of recognizing signs of participant resistance in performing research, the importance of reconsenting, and the ways researchers can consider how assistive technologies can resist or propagate broader societal biases [Williams and

Gilbert, 2019a, Williams and Gilbert, 2019b]. The set of skills that HCI researchers are expected to become well-versed in (e.g., data analytics or prototyping tools), must be expanded to include expectations for respectful engagement.

Even for trained study facilitators, study planning requires making tradeoffs between seemingly competing values and requirements (e.g., balancing the internal validity, external validity, time, and cost of a study). If accessibility is considered one of these optional tradeoffs, it will likely be under-prioritized, which our interviews show is not necessary or beneficial for achieving study goals. For example, Dhruv ended up prioritizing participant comfort over controlling dexterity using a between-subjects design. From a quantitative study design perspective, differences among participants' dexterity is a confound to be avoided. However, the risks of participant fatigue to data validity are much harder to address statistically than a between-subjects confound. Similarly, Christina* demonstrated that with a flexible protocol, collecting broader feedback did not reduce the quality of the research. As she explained, the protocol was adapted considerably for a participant with multiple disabilities, so the data collected from them was used to nuance and triangulate broader findings. The consistent theme here is that improving access improves the study and improved study access was not viewed by our interviewees as creating a burden or a deficit. While long histories of interpretivist and critical perspectives welcome subjectivity, lived experience, and difference, in some cases researchers may hesitate prioritizing these values while doing quantitative research. However, access should be prioritized as key in strengthening the rigor of a study design. Reviewing quantitative research with this reorientation may motivate more experiments which are not directly recruiting people with disabilities to invite their participation and appropriate recognition of rigorous quantitative accessibility research.

However, making methods accessible was not only about adapting existing methods. In some cases, the adaptations led to new methods and ways of thinking about research [Metatla and Cullen, 2018, Spiel et al., 2019a]. The way crip time guided interviewees' decision-making is a use case in thinking about novel methods development. For example, John's "conversation resets" and Beresford's 8-second rule [Scott-Barrett et al., 2019] invite clarity and reflection that could further build and branch out from philosophies of slow HCI [Olsen and Malizia, 2012]. While people with disabilities should be welcomed into existing activities, access work has the potential to distill new methods [Dolmage, 2017], which benefits the broader HCI field, not just accessibility studies.

To aid in recognizing how access impacts methods, researchers can make access work more visible. We demonstrate an incorporation of access considerations into our method section (see section 3.2) and argue that elaborating on these details enriches paper critique. As there is an expectation to document other methodological choices in methods sections (e.g., those that protect different types of validity), we propose that similar space should be allocated to discuss access provisions. Making this information standard allows us to better learn from and critique each other's efforts. Moreover, courses and text books that teach research methods need to cover accessibility basics [Coyne and Nielsen, 2001, Lazar et al., 2017], at the least. But, they must also ensure that students are aware of their knowledge gaps and where they must learn more or consult experts.

Finally, we stress that conducting accessible research is not the same as conducting accessibility research. Whether our disabled interviewees did accessibility research or not, they encountered barriers to partaking in research. We therefore encourage all researchers, regardless of their focus, to run and thoroughly document accessible studies. Doing so sets the expectation that disabled people may be on their teams or among their participants, and moves the research community towards a position of recognizing and valuing access labor.

4.5.2 Creating Technology and Tools that Support Accessibility

Many barriers interviewees experienced stemmed from unnecessary assumptions about users' abilities embedded in technology. To start, study tools broadly need to be accessible, including tools for prototyping, data analysis, and collaborative writing [Das et al., 2019, Jain et al., 2020, Li et al., 2021]. Short-term mitigation could comprise of resources such as lists of inaccessible tools and accessible alternatives. Imagining one step further, a research study dashboard could include a feature that identifies common accessibility "bugs" in study plans and tools that help identify bias in data collection and analysis, mirroring systems defined in genderMag and inclusiveMag [Burnett, 2021, GenderMag, nd]. Relatedly, there may be opportunities for careful applications of machine learning to support specific access tasks, such as recognizing words that need to be explained or removed in plain language versions or offering images to support a concept.

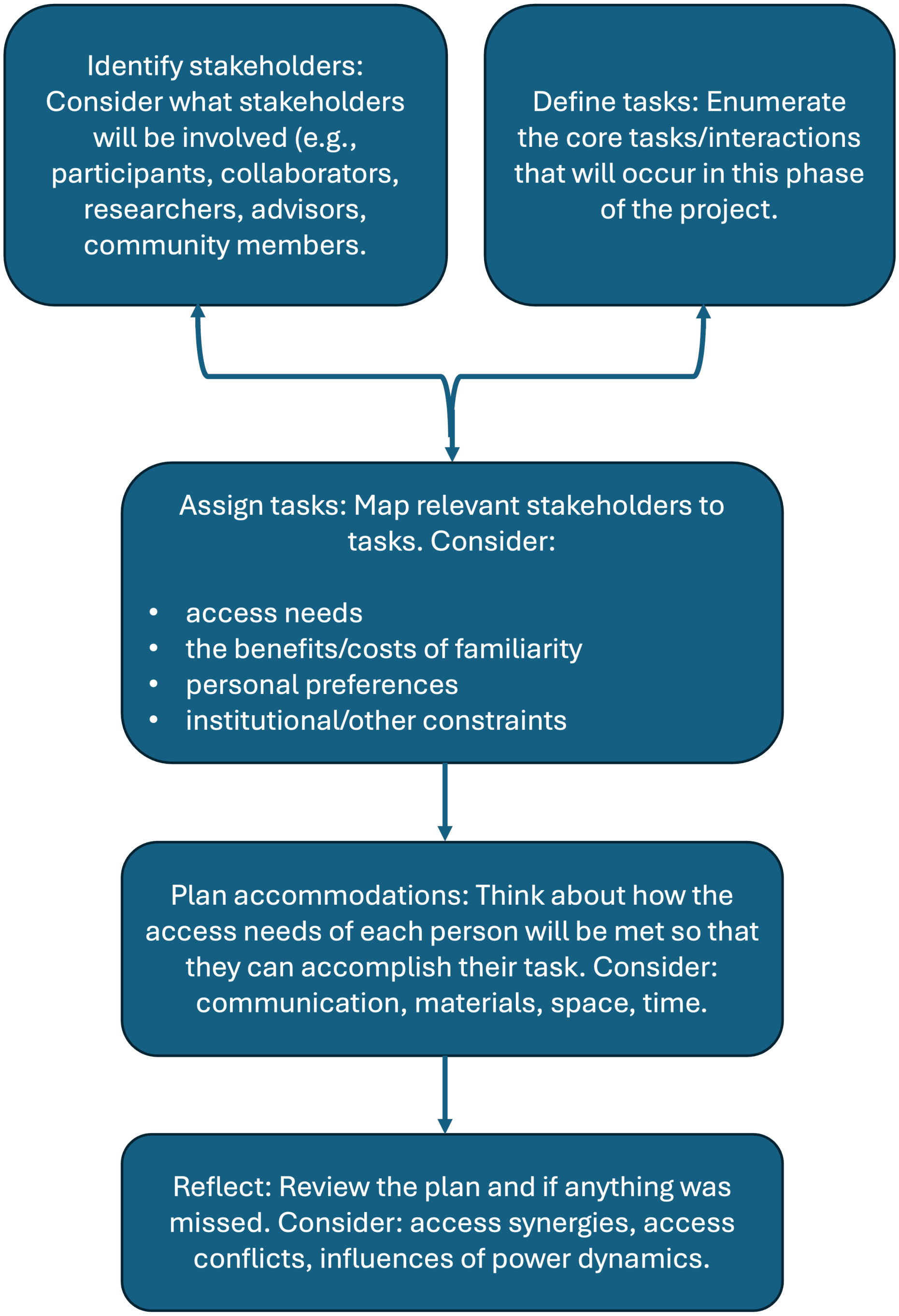
4.5.3 Navigating overlapping access needs

To be inclusive, studies have to be designed for a range of access needs. While prior work often focuses on accessibility for participants with a single disability, our interviewees broadened such considerations including people with multiple disabilities, negotiations between facilitators and participants, and communication and adjustments necessary for the collaborative work of running studies accessibly.

Often, study design came with ability assumptions of participants, which could further exclude those who have multiple disabilities, and therefore different access needs. However, these exclusion criteria are often not mandated by our research questions but by scoping choices. While it is reasonable, for example, to test a highly visual-based interface with sighted DHH people, this might erase the views of multiply disabled people, such as those who are DeafBlind. We found that these ability-based assumptions sometimes led to studies with explicit exclusion criteria, which were occasionally expanded after researchers met with participants who hadn't disclosed additional disabilities. In contrast, some of our interviewees modeled widening inclusion criteria. For instance, Christina* met a participant who could not access the study as designed. Her pivot from the task-based study outlined in her protocol to a conversation with this interested participant demonstrates the value of treating the experiences of participants with unanticipated access conflicts as not out of scope but rather as an opportunity to deepen knowledge. As the interpretation and translation examples throughout our chapter demonstrate, successful systems need to anticipate a diversity of users and interaction paradigms, and embracing variation within participant pools could help generate research outcomes that are more relevant to the ecosystem they exist within. In other words, if a primary use case of a technology is to provide visual feedback, people who do not or cannot benefit from visual feedback could ensure that the system is compatible with nonvisual alternatives like braille and text-to-speech that collaborators may be using. We recognize that universally accessible research prototypes are infeasible; however, we urge study facilitators to consider alternative ways to engage with participants with a broader range of abilities to triangulate other data. Welcoming those who a technology was not primarily designed for to participate in studies can overall create more inclusive solutions.

Research that is inclusive of multiple stakeholders with disabilities comes with its own negotiations. When suggested setups that are accessible for disabled participants are inaccessible to disabled facilitators, these conflicts can sometimes be resolved by the facilitator finding ways to make the suggested setup accessible to them, perhaps by involving campus disability services, hiring support (such as a captioner), engaging assistive technology or, collaborating with another team member. As some interviewees demonstrated, another option can be engaging participants in negotiating a solution that is equitably accessible to all, but this requires careful attention to power dynamics so that participants feel comfortable sharing their access needs. Heather* accomplished this through starting with humor and vulnerability in sharing her own needs, exemplifying that sharing access needs was encouraged. However, sometimes access needs are in stark conflict and cannot be fully satisfied at the same time, and we suggest that facilitators plan a response in advance. This process should be oriented towards an equitable arrangement, but may be achieved by facilitators compromising on their lower-priority needs before asking a participant to compromise. The experiences our interviewees shared of their professional duties having disabling impacts underscores the need to invest in building strong structural backing for accessible work, rather than relying on individual negotiations. While accessible cultures and resourcing may not solve all problems (an interpreter does not automatically guarantee successful communication), as Mack et al. and others have argued, they create the scaffolding to explore a more complete range of accessible options (e.g., reconfiguring and testing furniture arrangements (John), delegating some participant communications to a colleague (Zack*)) [Mack et al., 2021b].

Finally, teams of facilitators with multiple disabled members often worked to meet multiple sets of access needs as well as other considerations such as personal preferences or childcare needs. In these scenarios, we suggest that teams adopt a lens of interdependence [Mingus, 2017]. When viewing teams as a unit composed of interdependent individuals, the team first defines their objectives and then discusses which person or group of people could best take on each task, balancing team goals with individual goals and preferences as well as hard constraints (e.g., access needs). We suggest that this approach to teamwork and team member interactions can be expanded to include other stakeholders in a project outside of team members (e.g., participants). We offer the following flow chart as a way to structure a facilitator's thinking about project accessibility. This chart could be completed or used as a brainstorming tool for all phases of the project outlined in Section 4.1 as well as for broader events related to the research process that transcend a project (e.g., lab meetings).



Identify stakeholders: Consider what stakeholders will be involved (e.g., participants, collaborators, researchers, advisors, community members.

Define tasks: Enumerate the core tasks/interactions that will occur in this phase of the project.

Assign tasks: Map relevant stakeholders to tasks. Consider:

- access needs
- the benefits/costs of familiarity
- personal preferences
- institutional/other constraints

Plan accommodations: Think about how the access needs of each person will be met so that they can accomplish their task. Consider: communication, materials, space, time.

Reflect: Review the plan and if anything was missed. Consider: access synergies, access conflicts, influences of power dynamics.

Figure 4.2: A flow chart that can be applied to plan how to address the access needs of each stakeholder for any stage of the research process outlined in Section 4.1, along with an example application of this workflow.

We now present a workflow to help guide researchers in planning accessible studies (see Figure 4.2). To use this diagram, consider an example of a team conducting interviews in ASL with Deaf participants. The team identifies that people involved in this stage include Kentrell, the project lead, Mei, a junior project team member, a team of interpreters, and the participants. The preliminary list of tasks includes hiring and scheduling the interpreters, printing out the interview questions to support communication, booking the space for the in-person interview, asking the interview questions, and answering the questions. In dividing up the tasks, the team considers Kentrell's access needs: he is chronically ill and fatigue variably affects his ability to think and limits the number of "workable" hours he has in a day. Mei does not list any relevant access needs, and the participants will all be Deaf and use ASL. As project lead, Kentrell would prefer to run interviews. The team decides Kentrell will ask the interview questions and book and prepare the room before interviewees arrive (e.g., selecting a large, open room that has natural light). To reduce Kentrell's administrative tasks, Mei will work with their institution's accessibility providers to schedule the interpreters, print the interview questions, and reconfigure the interview room to optimize sight lines and remove visual distractions. During an initial interview, Kentrell learns that his and participants' access needs may conflict – interpreters must be hired at least a week in advance, but Kentrell's fatigue might require him to stop facilitating an interview last minute. Interpreters must still be paid if sessions are not rescheduled with 24-hour notice, and rescheduling increases participant burden. So, Kentrell asks another researcher looking for mentorship in interviewing from his lab, Luz, to join the project. As part of her contribution, Luz will attend interviews, ready to take over from Kentrell as needed. In return, Kentrell mentors her on accessible interviewing techniques and doing research with the Deaf community.

We recognize both the potential benefits and drawbacks of adopting such a model of interdependence in planning. Adopting such a planning workflow described in Figure 4.2 may normalize the discussion of all access needs (not just those derived from disability) and therefore lessen the pressure shouldered by junior team members to start such conversations. However, Shoshana and other researchers [Das et al., 2019, Ymous et al., 2020] explained the potential reluctance and repercussions of disclosing in less supportive environments created by the overlapping effects of power structure and potential disability stigma or discrimination. We suggest that teams consider how best to adapt the workflow described in Figure 2 so that it is most applicable to their context and provide sufficient anonymity, if necessary, so that the team as a whole can address access needs without individual team members facing repercussions.

Finally, we propose that this workflow provides further benefits as a form of access mapping, which has had previous success at instigating institutional change. Currently, there are gaps in the accessibility support offered by institutions, besides interpreter and captioner scheduling services [Jain et al., 2020, Shinohara et al., 2020, Shinohara et al., 2021]. To better identify where institutional support is needed in the process, we suggest that recording the current barriers in making projects accessible is critical (e.g., in methods sections, in discussions with institutional review boards). Historical examples of mapping (in)accessible physical spaces such as the Mapping Access [Hamraie, 2016] Project Sidewalk [Saha et al., 2019, Project Sidewalk, nd] and PISSAR (People In Search of Safe and Accessible Restrooms) [West, 2010] projects were used to collect data to support broader, institutional change. Identifying and documenting the common accessibility issues or areas lacking support when mapping the access of a research project can help provide political leverage for the need to increase institutional support.

4.6 Limitations

While we argue that all research methods should be made accessible, our interviews were non-representative. First, our participants were North America-based and though we recruited community organizers, they represented a minority of interviewees. Regarding interviewee experience, in particular, we had few who were expert experimentalists, quantitative analysts, and participatory designers. We point readers to complementary resources [Brulé and Spiel, 2019, Lazar et al., 2017, Williams and Gilbert, 2019a]. Future research should take up different approaches by perhaps conducting workshops to co-create accessible methods guides or using non-retrospective methods (e.g., documenting accessibility attempts along-the-way or testing the efficacy of specific techniques) and attempt to recruit a more geographically and experientially diverse group of participants. While our method lacked the diversity of sample that could have been achieved with a method that focuses on breadth (e.g., surveys), our method did allow for participants to recount experiences in detail, include context, and discuss conflicting priorities. Such depth would have been improbable to receive from something like a survey response where participants rarely write lengthy reflections in free response fields.

Additionally, taking up Heather*'s and prior work's [Yıldız and Subasi, 2020] awareness that disability disclosure may have different impacts on research, our disclosed and visible similarities to and differences from interviewees may have impacted the details shared. Finally, our median interviewees' five years of experience skewed toward early career designations in academia. Additional contributions from senior scholars and organizers will strengthen future research.

4.7 Conclusion

The process of conducting and participating in studies determines whose voices are heard, and welcomed, in human-subject activities. Often, accessibility is not considered or treated as an afterthought when planning studies, and little space in papers is given to discussing access work. Through our interviews with 17 experts in providing access to people with disabilities in common HCI activities like interviews and workshops, we collected, analyzed and shared a diversity of examples around associated access work and negotiations. We learned that access must be enacted throughout the process. We identified four key dimensions (communication, materials, space, time) and a common strategy of "anticipating with adjustments" among our participants. Our work aims to shape norms around access labor by making it visible in papers and a core consideration of study planning. We contribute an accessibility planning workflow to help people reach this goal and suggestions for how technology can encode a norm of access.

Chapter 5

MIXED ABILITIES AND VARIED EXPERIENCES: A GROUP AUTOETHNOGRAPHY OF A VIRTUAL SUMMER INTERNSHIP

This chapter is based on [Mack et al., 2021b] (screen reader accessible) and [Mack et al., 2023].

5.1 Introduction

In this work, we examine the interplay of virtual work and mixed abilities to help address such problems and enrich the growing field of work about virtual engagement. Utilizing an autoethnographic research method, 11 of us who were members of or affiliated with Microsoft's Ability Team journaled about our experiences on the mixed-ability team for three to four months. Five authors, whom we refer to as "meta-authors," then iteratively examined the data, to identify five key, interdependent themes. We experienced several *virtual (in)accessibilities* that arose from the new, online context. As this was the first virtual internship and the Ability Team's intern cohort with the most diversity in abilities, we experimented with ways of establishing and executing accommodations in the workplace. We quickly found that the list of mixed-ability accommodations we needed to follow was *difficult to remember*, and in some cases, accommodations *conflicted with each other* in ways that had not been experienced in person. Finally, we discussed how important *allyship* was this summer, and how *power dynamics* impacted overall accommodation success.

We also created a set of guidelines around how we would advise those in similar situations, reflecting on the norms and accommodations which we established for the summer that were successful in promoting access and those that could be further improved. These guidelines focus on 1) the community co-creation of norms that leverage interdependence and shared vulnerability, and 2) the invisibility of accessibility failures and access labor.

In summary, this work contributes: (1) in-depth accounts on five key factors that influenced our experiences (virtual inaccessibility, difficulty remembering access accommodations, conflicting accommodations, allyship, and power dynamics), (2) reflections on how these factors interplayed and helped or hindered the accessibility of the group, and (3) a set of guidelines for future virtual mixed-ability teams.

In this chapter, I continue identifying factors that can allow technology designers to better anticipate how accommodations can change for people with disabilities in group contexts. Specifically, this autoethnographic reflection demonstrates how the factors of spacial context, social context, and visibility of disability can impact access provisioning, and therefore how people with disabilities engage with technologies. Notably, these factors start to look beyond a person's individual abilities and turn to more external factors like the environment of use, the composition of the group, and social dynamics. These factors highlight that providing access to a group can be involved or complicated, especially if people have conflicting access needs. Therefore, in the discussion in this section, we discuss how technology and teams can establish and enforce access norms together.

5.2 Related Work

5.2.1 Accessibility in Remote Work

The sudden shift in work practices due to the COVID-19 pandemic, coupled with demonstrated productivity [Parker et al., 2020], has strengthened the argument for the feasibility of remote work. Increased acceptance of remote work raise new employment opportunities for people with disabilities [Schur et al., 2020]. However, researchers have begun studying how discriminatory organizational policies [Gleason et al., 2020] and lack of accessibility in remote collaboration tools [Tang, 2021] may perpetuate and replicate accessibility challenges in remote work. For example, during remote meetings, deaf and hard of hearing people need to navigate multiple visual channels for access (e.g., lip reading, American Sign Language (ASL) interpreter video, captions) while simultaneously following presenter slides and chat threads [Kushalnagar and Vogler, 2020]. Neurodivergent people who have autism, attention deficit/ hyperactivity disorder, learning disabilities and psycho-social disabilities must also navigate various sensory and cognitive stressors [Zolyomi et al., 2019] and negotiate for accessible communication practices during remote meetings [Das et al., 2021]. Collectively, this growing body of research sheds light on the access needs of people with disabilities in coordinating and communicating over remote collaboration technologies when teams are distributed in time and space and outlines guidelines and best practices for improving accessibility in remote work [Tang, 2021, Das et al., 2021, Kushalnagar and Vogler, 2020]. We extend this body of work by presenting and reflecting on our remote work experience as a team that includes disabled and non-disabled people with a variety of accommodation needs.

5.2.2 Accessibility in Mixed-Ability Collaboration

A growing body of literature within HCI investigates accessibility in mixed-ability teams. Bennett et al. [Bennett et al., 2018] put forth the concept of interdependence, which draws on disability studies and activist work [Invalid, 2019]. Access is conceived of as co-created and sustained through "relationship between people and things." Related prior work has explored the ways in which blind and sighted people collaboratively establish accessible living space [Branham and Kane, 2015a] and perform shared tasks such as writing [Das et al., 2019] together. A common thread in prior work is that accessibility is produced through "care work" [Piepzna-Samarasinha, 2018] where people with and without disabilities continually attend to each other and fluidly adapt their work routines [Bennett et al., 2020]. For instance, Jain et al. shared how graduate students with disabilities and their able-bodied allies established "uncharted accommodations," and minimized accessibility issues by customizing technologies in-situ [Jain et al., 2020]. Still, these studies revealed tensions arising when people with diverse access strategies collaborate [Jain et al., 2020, Das et al., 2021], and how people compromise and work through conflicting access needs [Hofmann et al., 2020, Das et al., 2021]. Situated in this emerging literature, our work brings in new perspectives by exploring all-virtual mixed-abilities collaboration.

5.3 Methods

Our approach to data collection and analysis follows autoethnography, a qualitative research method where the researcher positions themselves as the participant and collects and examines data through self-reflection detailing their lived experiences within particular socio, political, and cultural contexts [Desjardins and Ball, 2018]. In the past decade, autoethnographic methods have been increasingly used in HCI research to foreground rich personal insights that often cannot be captured through other research methods [Desjardins and Ball, 2018, Lucero, 2018]. In our project, we had two types of contributors: authors (6 people) and meta-authors (5 people). All authors and meta-authors participated in data collection. The meta-authors led the data analysis and writing.

5.3.1 Data Collection

Data collection began in June 2020 and consisted of two artifacts: fieldnotes – notes documented within a week of an 'event' with people with mixed abilities, and retrospective accounts, – accounts of past events generated from memory. Each fieldnote or retrospective account contained a narrative description of the event (including technologies and stakeholders) and the writer's personal interpretation (including emotional responses). Events included social meetings/team morale events ($\sim$20-30 total, though not all had relevant experiences to journal), weekly team meetings ($\sim$20 total), Microsoft Research-wide social events ($\sim$5 total), and organized intern events. In total, the retrospective accounts and fieldnotes document experiences of 11 people in about 6,000 words.

We established privacy in our journaling process by allowing contributors to report in separate documents that were not shared with the other contributors. Only the meta-authors were able to see this data, with explicit permissions from the contributors.

5.3.2 Data Analysis

The experience reports were analyzed using open, axial, and selective coding to articulate the social, cultural, and personal implications of mixed ability environments. At the beginning of the analysis, the first author read the experience notes and created eight initial codes (e.g. hidden access needs, power dynamics). These codes were shared with other meta-authors and revised based on critical discussions, which included adding other salient codes and removing or merging codes. This process generated nine axial codes. To ensure external validity and avoid misinterpretation [Lucero, 2018], the final axial codes were shared with the authors, who coded their own experience reports under these codes on a shared document. During this process, we also allowed any new reflections on the contributed data relevant to the axial codes. Finally, the axial codes were combined into the final five overarching themes presented below, and exemplary vignettes were collected from the notes. These themes, codes, and vignettes form the foundation of this autoethnographic narrative. The drafts of this work were shared at various stages with the authors.

5.4 Team Composition and Dynamics

As a result of the COVID-19 pandemic, Microsoft had its first all-remote summer intern cohort, which introduced accessibility and other challenges. Additionally, the group of interns hired by our team, the Ability Team, had a diverse range of abilities. We describe the team and internship experience to contextualize our findings around working on a mixed abilities team in a fully virtual, industrial setting.

5.4.1 Biographies

The Ability Team consisted of a diverse set of individuals with respect to their backgrounds and identities. Full-time Microsoft employees with a range of experience in industry and Microsoft served as official and unofficial mentors of the Ability Team interns or other teams that overlapped in focusing on accessibility. All of these official Ability Team members and affiliates attended weekly hour-long meetings to discuss research topics.

The meta-authors consisted of two full time employees, who work in the accessibility area, and three PhD student interns, two of whom are disabled. Of all authors, five identified as Asian and six as white. Four authors identified as women and eight as men. The average age was 32.9 years (range 24-60 years). [1] The disability status is summarized in Table 5.1.

Finally, in this chapter when we refer to the experiences of disabled interns, we refer only to those who disclosed their disability status and chose to share their experiences with us, though there may have been other disabled team members. The experiences of the disabled interns who contributed to this work do not necessarily extend to other people with disabilities on the team.

5.4.2 Regular Activities and Technical Infrastructure

In Microsoft's first ever all-virtual internship, the Ability Team replicated many in-person experiences typically offered during summer internships. Work meetings, such as the weekly Ability Team meeting that existed pre-COVID, persisted in virtual form over group video calls. During these meetings the team introduced interns, shared announcements, discussed research, and gave

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[1] One person abstained from specifying their age.

Table 5.1: The demographics of the six authors and five meta-authors who participated in this autoethnographic study. This is a single column figure as per the new ACM template.

Name	Position	Disability Status
Mack (meta-author)	Intern	Disabling chronic illness
Das (meta-author)	Intern	None
Jain (meta-author)	Intern	Hard of hearing
Bragg (meta-author)	Full-time Researcher	None
Tang (meta-author)	Full-time Researcher	None
Andrew Begel	Full-time Researcher	ADHD
Erin Benetau	Intern	None
Josh Urban Davis	Intern	None
Abraham Glasser	Intern	Deaf
Joon Sung Park	Intern	None
Venkatesh Potluri	Intern	Blind

presentations. To replicate impromptu socialization, the Ability Team manager created weekly meetings intended for non-work conversation. Interns created their own weekly lunch chats among themselves, which became an informal social space.

Microsoft Teams and email were the primary tools used to support remote collaboration and communication. Microsoft Teams is a combined communication tool and file management system. Both direct messaging and channels for groups of employees were made for text-based conversations. Video calling was a supported and integrated feature that rapidly evolved as Microsoft Teams became more popular and released new features. In video calls, users were able to turn on and off their camera and microphone. Microsoft Teams automatically arranged the videos shown to a user, prioritizing people with their cameras on and who are speaking with their voice. However, users could curate who was shown on their screen through a pinning feature. At the beginning of the summer, a maximum of nine videos could be shown at a time (the limit has since been increased). A text-based chat was also available during each video call, allowing for simultaneous communication across two main channels; this chat persisted after the meeting ended. Users could also share their screen or an application window, supporting presentations to the group.

5.4.3 Accessibility Accommodations

Accommodations were requested this summer to ensure that interns with disabilities had equitable access to all materials and events. These accommodations mainly took two forms: accommodations that people with disabilities established for themselves, and accommodations that required changing norms among the full team.

Self-established accommodations were controlled by the intern with a disability and included requesting an ASL or visual interpreter or a captioner who are often critical for access to meetings and/or company-wide intern events.

Other accessibility accommodations were *norm changes* that required effort and commitment from all team members to be successful. Accessibility guidelines for the team meetings were established at the beginning of the summer by the manager of the Ability Team. Interns at Microsoft had different start dates, leading to frequent changes in the disabilities represented in the team. Consequently, the Ability Team manager sent out an email every week with the list of accommodations to be followed. While this email was circulated regularly, this information was not available outside of email. The final **list of best practices** included: 1) speaking slowly for captions 2) saying your name before speaking to help with speaker identification, 3) making presentations accessible (included links to best practices), and 4) avoiding triggering motion sickness from causes including a shaky camera (e.g., while walking) and scrolling during screen shares.

5.5 Findings

Through working on a mixed-ability team this summer, several interconnected themes arose as key factors that impacted our experiences. We encourage readers to read the entire section, even if they are seeking information about one theme, as the understanding of an individual theme is incomplete without understanding of its interplay with others.

Our experiences this summer were shaped by the intersection of our diverse backgrounds, our technological tools (Teams), and our accessibility group norms. To demonstrate the complex interweaving of these key factors, we share a short story from our time together.

5.5.1 Vignette of Our Experiences

One meeting, Jain, who is hard of hearing, presented to the group. Jain was on mute and started sharing his screen, which meant that he could only see his own video and the video of the most recent speaker. While we tried to alert him that he was still on mute, it seemed impossible to get his attention. Since we knew he could not hear us, we tried waving our hands and typing messages in the shared chat; nothing worked. Eventually, one participant made a paper sign that said "you're on mute", but even that took a while to become visible because that person had to speak long enough for his video to be shown to Jain. This experience pointed out a cascade of accessibility problems with video conferencing software while sharing slides that disrupted the meeting.

5.5.2 Virtually Induced (In)Accessibility

Meeting exclusively through online collaboration technologies directly impacted accessibility, especially because many of our group meetings included a mixed set of abilities, assistive technologies, and accommodations. Meeting virtually did provide one accessibility advantage [Tang, 2021]: the inclusion of text chat in all video calls [Sarkar et al., 2021] meant that people could easily choose a modality of contributing that fit their abilities. However, our mixed ability team communicating in a fully virtual space did result in several accessibility challenges largely revolving around 1) incompatibility between video-conferencing software and assistive technologies and practices employed by people with diverse abilities, which often led to 2) decreased visibility of disability and increased access labor.

Our video conferencing software created several access barriers. Participants who used ASL often are quiet or muted when they sign, whereas the video conferencing software uses audio only to prioritize which video streams to display. Therefore, those participants' video feeds were rarely shown. To address this issue of video prioritization, we recommended an accommodation of pinning the video of ASL users. However, this distributed solution required each meeting participant to individually remember to do so, as there was no mechanism to pin that video stream for everyone. Bragg reflected: *"It was quite frustrating to me when my mentee's video [who was deaf and communicated via ASL through an interpreter] was not included in the set of videos displayed during large meetings ... it seemed that in many cases the other meeting participants were happy to con-*

tinue without taking action to remedy the situation." Not seeing the signer meant that the expressive affect of the person was lost. It also resulted in confusion among participants over who was contributing (e.g., confusing the interpreter for the deaf individual), and more generally, unequal access and inclusion.

Seeing a signer clearly was more challenging when a participants shared their screens. The video call's interface gave more screen space to screen sharing, which was afforded by reducing the number of video tiles and the space for live text captioning. This limited screen real-estate when screen sharing could mean losing sight of an ASL interpreter, unless their video tile was pinned. Bragg and Glasser's lab spent considerable time developing a protocol that involved pinning interpreters and then screen sharing. This solution was not perfect (technical issue arose) and it took many rounds of iterating, escalating, and collaborating with technical support and leadership to get implemented.

Another issue with ASL interpreters was that they appeared in the video conferencing software's interface without any information about whom they were supporting. Park commented that, in the context of in-person meetings, ASL interpreters were typically positioned across from the person they were supporting and clearly maintained eye contact with them. In contrast, ASL interpreters in the video conferencing software appeared in their own video tile, often without explanation, and were unlinked to the people they supported. This lack of context around interpreters sometimes created confusion, especially early in the summer. Introducing new interns from a list of meeting participants became awkward when people did not realize if an unfamiliar person was a new intern or an ASL interpreter.

Similar to ASL interpretation issues, captioning delays led to less equitable access to DHH caption users, particularly in online settings that limited the shared awareness of those delays. Turning on live text captioning was a choice for each participant, leaving some participants unaware of the delay. Begel, after turning on captions, reflected: *"I never noticed before that Teams' captions have a delay which led to me reading the caption of the [one] speaker as another person already started talking. That led to some difficulty following the thread of the conversation whenever it moved through the DHH speaker."* This delay was even less visible if someone was using a private captioner or interpreter, which wasn't seen by any other meeting participant. Because there was no shared awareness of these delays, people were not getting feedback on how to pace their conversations relative to the delays involved in communicating with everyone.

Moreover, the limited view that meeting participants saw of a disabled intern often did not include their accommodations. For example, participants using captioners or interpreters often performed a considerable amount of access labor, which involved joining the main meeting and a separate video call on a separate device with an interpreter. However, this labor was obfuscated by the video conferencing software.

As a consequence of this hidden access labor, inaccessibility in virtual settings was great, perhaps greater than in-person meetings, when norms or accommodations were broken. For example, the absence of a captioner is easy to miss in virtual meetings, whereas it would have been visually obvious to sighted people during in-person meetings. Colleagues may adjust their speaking speed or come up with more accessible modes of communication, but only if they are aware of the captioner's absence. Similarly, one intern, Mack, experienced severe motion sickness that was triggered by several video presentations in meetings over the summer, which was almost impossible to notice virtually. Davis noted: *"After presenting my research at the lab meeting, a fellow intern mentioned to me that one of my slides with a time lapse video as the background caused them severe nausea. I had no idea this could potentially be an issue ... The intern said that they often didn't mention these things ... I wish I had known sooner."* Mack had to choose either repeatedly getting sick from people's videos without their knowledge or starting a direct conversation with a colleague.

While access to multiple modalities for communicating (video, audio, text chat) enabled some accessibility opportunities, it also introduced challenges in demanding much attention during a meeting. The text channel was often used for concurrent side chat or sharing information like links. This problem of split-attention, while experienced by non-disabled virtual meeting participants [Sarkar et al., 2021], may be exacerbated for disabled participants. For example, Potluri reflected: *"Our computers' ability to help us multi-task induces stress because of a perceived expectation to be at multiple places (in a meeting + an other chat for example) at the same time ... With both the meeting audio, and the screen reader blaring notifications in my ears, I couldn't concentrate on the meeting after a point and I even dropped off a few meetings as I felt that I was being disrespectful to the speaker by pretending to be there, and not really listening."* Attention splitting was also felt by Jain who had to follow captions and chat content.

5.5.3 Power Dynamics

Upholding accommodation norms was a core value of our team, but *power dynamics* affected success. Das noted: *"Following "best practices" or guidelines that come from top down... helps to set the tone of the meetings and make others aware and mindful of adapting to practices that are more accessible."* For instance, in the Ability Team meetings, we found that if senior members announced their names before speaking (or did not), others were more likely to follow.

Team hierarchy made it difficult for junior team members to advocate for behavior changes. One intern, Mack, felt inner conflict when senior researchers were not following the norms: *"I occasionally put a reminder of 'are we still saying our name before we speak?' in the chat, but it felt so weird to correct others when most of them are very senior researchers who you are hoping will think highly of you when you're on the job market."* She wanted to make a good impression, and was uncomfortable correcting people in more powerful positions. However, she also felt guilty if she did not address those breaking the norms, as reminding people to adhere to accessibility practices is an important part of being an ally.

At the same time, it can be difficult for senior team members to determine when their advocacy will help or harm. Bragg presents such an internal conflict created by power dynamics: *"As a mentor... it can be difficult to strike the right balance between shielding the intern from having to advocate for themself, and making sure that you are not speaking/advocating for them unwantedly."* Someone in a position of power, like Bragg, can help improve access by setting an example or addressing accessibility issues. However, an intern may not always want to draw attention to their disability or access needs. Interns may also prefer to advocate for themselves, knowing their own needs best. A mentor advocating in these situations may feel embarrassing or patronizing. Such concerns may prevent senior team members from speaking on behalf of more junior members, even while aware of accessibility issues.

5.5.4 Difficulty Remembering Accessible Practices

Keeping track of and implementing multiple accessibility practices while also engaging in meeting content proved to be a challenge for many meeting participants. Participants entered each experience with the intention of inclusivity, but struggled to maintain inclusive behaviors. This drift away from adherence to guidelines occurred during individual meetings, but also over the course of the summer. The list of accommodations shared was lengthy and verbose and difficulty implementing accommodations seemed to correlate with how clearly the accommodations were outlined. In particular, the group largely failed at implementing accommodations related to motion-sickness, which were all grouped together into a single bullet, regardless of when and how the accommodations needed to be implemented. This was likely a result of how these accommodations were curated – requested by individuals with particular disabilities – rather than by how they would need to be consumed (e.g., norms for presentations or conversations).

Difficulties implementing accommodations were compounded by the novelty of the accommodations to some people. Many team members had experience with *some* disabilities, but not all of them. As a result, nearly all meeting participants faced a learning curve in learning how to follow accessible practices. Tang added: *"I remember the first time I was called out for not verbally identifying myself before speaking at the [team] meeting on July 2, I quickly moved from being annoyed to realizing I needed to learn a new practice, and it just took a little nudge for me to make that shift — I think we needed more of that throughout."*

Changes in the set of accommodations that needed to be implemented in different meetings due to the *variation in group membership* further complicated the task. The set of meeting attendees was not constant, and as a new disability appeared or disappeared from the group, the list of accommodations that needed to be top of mind changed. This summer, the attendee list was particularly prone to fluctuate, as interns began and ended their internship experiences on different timelines. Bragg reflected: *"It becomes increasingly difficult to always remember all of the accessibility protocols during meetings as the number of disabilities grows ... This becomes more difficult if you are an occasional meeting participant, and if the set of disabilities/accommodations changes over time."*

Likely as a result of the cognitive overload, it was common for people to drift away from the guidelines. For example, meeting discussions would often begin with each person saying their name as they began to speak, but would be abandoned by the end. Participants entered each experience with the intention of inclusivity, but struggled to maintain inclusive behaviors. This drift away from adherence to guidelines occurred during individual meetings, but also over the course of the summer. Davis commented: *"I noticed each week that there was a solid attempt to say our names prior to* *speaking. However, as the meetings continued, this practice rather quickly deteriorated."*

5.5.5 Conflicting Access Needs

Maintaining coordination and communication among people with diverse abilities led to situations where access needs conflicted with each other [Hofmann et al., 2020, Das et al., 2021]. For example, Teams' limited screen real-estate during screen sharing often excluded the interpreters' videos. Bragg described the dichotomy in presenting during meetings to ensure interpreter visibility: *"...we came up with a protocol where the meeting presenter shared their screen, which included both the pinned interpreter and the meeting slides. This enabled everybody in the lab to view the interpreter at a reasonable size while simultaneously viewing the [presentation]. However, sometimes this resulted in the slides (especially text) becoming prohibitively small to read."*

Other accommodations could increase access in one dimension while decreasing access in another. For example, performing allyship through backchannels can increase access through advocacy, but splits attention [Sarkar et al., 2021], as Jain and Potluri noted earlier. Relatedly, Benetau, a sighted, hearing person, described challenges in adapting to the influx of information in multiple modalities during a remote meeting with automatic captioning. She was distracted and overwhelmed since *"the speaker used a high rate of speech so there were lots and lots of words being typed on the screen, more than I would be able to read at a time, and they were also disappearing faster than I could keep up."*

Further, creating content that everyone could participate in required carefully navigating conflicting access needs. We observed a striking example of this challenge during a challenge to make a piece of art that the full group could enjoy. Davis reflected in his experience making a video submission (one frame shown in Figure 5.1): *"I spent a considerable amount of time brainstorming multimodal sensory recordings that would be usable by as many people in the group as possible. Recording the ducks, for example, took over an hour and a half and comprised 37 separate recordings because I needed the ducks to be visible, make a sound, and not have the camera move too much (since a shaky camera phone recording could cause motion sickness)."* Davis's experience sheds light on the care and labor needed to make content multimodal, so that diverse team members could access them.

Figure 5.1: A frame of Davis 's multimodal scavenger hunt submission, a video of ducks swimming and quacking.

5.5.6 Allyship

Allyship was key for gaining access and feeling supported in lapses in the Ability Team and company-wide events in following accessibility guidelines. Being fully online provided a unique new channel for allyship: back-channeling via text messaging. Allies harnessed both the group chat associated with each meeting and direct messaging for allyship, allowing allies to explicitly or implicitly call out inaccessible practices. For example, as stated earlier, Mack and other team members throughout the summer used the chat to remind people to say their names before speaking — an explicit reminder. The chat could also be used to mitigate accessibility issues and share implicit reminders. Das reflected: *"when the work anniversary video was being played without description, an intern quickly wrote down a short description of the video on chat. She wrote, 'alt: pictures from M's friends. ranging from Mt. St. Helens to Texas, pictures of M and his spouse hiking, thank you's from [team members] saying how much they love the hikes he suggested.' Six team members 'loved' this message and two others 'liked', including one of our interns who is blind. I think it was a very thoughtful and nice gesture from the intern who proactively provided this alt-text."* This method of making up for omitted alt text in the chat was a reasonable, in-the-moment solution [Jain et al., 2020]. However, splitting a user's attention between video and chat is not ideal. Therefore, the public meeting chat was a way to mitigate accessibility issues, but was no replacement for prepared, accessible content.

Power dynamics seemed to influence allyship, as more senior team members often had less visibility into discussions about access issues, access labor, and allyship. In contrast, most interns regularly engaged in deep discussions on these topics. We suspect this difference in experiences between full time employees and interns could be due to several factors. First, power dynamics cause tensions between mentors and interns when providing allyship, as Bragg described earlier when she tried to strike a balance between being an ally and not being over-eager. Second, power dynamics often affected the type of information that was conveyed in conversations. For example, one disabled intern, Mack, grew to be close friends with one of the interns this summer, Yamagami. Because of their connection and frequent communication, Mack shared her daily accessibility issues with Yamagami. In turn, Yamagami became a strong ally for Mack; she would speak up about aspects of events that were problematic for Mack after checking in with her when she felt too shy or bothersome to say them herself.

On the other hand, Mack did not message her manager or other senior team members regularly, and therefore didn't build this same level of connection with them. Thus, they were not privy to her daily challenges. As Tang noted: *"I think I only became aware of Mack's sensitivity to motion in videos because of the multi-modal scavenger hunt, which is well into the summer season, and if I wasn't consciously aware of it, I wouldn't have known to need to warn about potential motion sensitivity."* Without hearing about the inaccessibilities Mack faced or seeing the effects of triggered motion sickness, Tang was, in a way, excluded in performing effective allyship.

5.6 Discussion

We reflect on themes arising from our unique setting of multiple people with varying abilities involved in a virtual summer internship. Our work joins that of others who call attention to the ways *access is created by establishing group norms* [Jain et al., 2020, Das et al., 2019, Thieme et al., 2017, Kushalnagar and Vogler, 2020, Bennett et al., 2018]. Furthermore, our reflections revealed that the community's ability and commitment to adhere to these norms determined how supported disabled interns felt and how effectively they could engage with the work content. We then discuss how the *invisibility of access labor and disability* could be beneficial or harmful to an individual depending on their desire to disclose their disability.

5.6.1 Community Norm Making

In this section, we dive into the mechanics of our groups' accommodations to understand why we, members of the accessibility research group, still struggled to reach full accessibility.

Norm Selection

The formation of community accommodation norms (i.e., those norms that strengthen accessibility) were crafted according to the individual needs of each disabled intern and changed regularly as interns joined and left the team. Due to the sudden global pandemic, the team needed to choose how and which norms from in-person interactions to translate to a virtual setting. Some common in-person accessibility norms (e.g., speaking clearly for an interpreter) were adopted in a virtual space without much alteration. Other norms became unnecessary. For example, a common norm is to not touch a disabled person without their permission, which was inherently satisfied by the virtual context.

In other cases, norms were not translated to a virtual space which caused inequity or confusion. For example, a common norm shared with groups working with signing d/Deaf individuals is to speak to and look at the d/Deaf person, not their interpreter. This in-person norm required adaptation, as verbally communicating interpreters' videos were prioritized over d/Deaf signers'. However, this issue was not identified until the internship began and was not addressed until weeks later.

Recommendations: Rather than requesting or establishing norms individually, we recommend holding a team discussion to establish norms *collectively* and *holistically*. In such a model, all of the access needs of team members can be viewed at once. This structure allows for a more holistic approach of norm creation rather than siloing the accommodations for each individual, and could help minimize access conflicts. Additionally, drawing from interdependent models of communities [Bennett et al., 2018, Invalid, 2019], this process could lead to more accommodations with benefits for multiple people, including those without disabilities in the team. As Sins Invalid notes: "Everyone has access needs, and they can be talked about without shame" [Invalid, 2019].

It is important to note that a few factors complicate this process of community norm formation. First, community discussions including non-disabled and disabled team members about their needs require vulnerability [Shinohara and Wobbrock, 2016, Cory, 2005], and it might not be safe to do so. One way to mitigate this issue could be to encourage all group members, regardless of disability status, to list access needs. For example, a team member who is also a parent might ask that meetings not be held earlier than 10 AM to allow for school preparation. This norm might benefit disabled team members, but it also normalizes asking for changes.

The second way in which this community-based norm creation process can be complicated is due to changes in group membership over time. Consequently, we suggest that communities develop a regularly scheduled time to review and adjust norms, which both facilitates the onboarding of new group members and benefits people whose needs change over time. A regularly scheduled review of the norms means there is an established pathway for a person to request changes to norms, which can be more comfortable than instigating a review-of-norms on one's own. MackRelatedly, since it is near-impossible to foresee and plan for all access barriers, regularly scheduled team conversations allow accommodating new barriers as they emerge.

MackFinally, when shifting to a new context (e.g., in-person to remote), groups may explicitly consider both how norms from the prior context might be transferred over and what new norms are needed. This time can also be used to reflect on if access needs that weren't being met in person can be addressed more successfully in virtual spaces.

Norm Sharing and Teaching

We recognize several ways our large list of emailed norms grouped by disability was potentially ineffective. First, the *list was updated* without much announcement. Therefore, it was easy to skim the list and not internalize the new norms or otherwise miss updates. Second, the list was organized by disability. The norms specific to one activity (e.g., presentations) were scattered throughout long bullets of text. Finally, the list *omitted background information*, for example, explaining how interpreters are used or how a screen reader is used. Our experience highlights that a comprehensive background in accessibility cannot be assumed, and that without the background information, norms may not be carried out effectively. For example, Tang realized that he had not consistently carried out the norm of announcing his name before speaking, since he mistakenly assumed that it was unnecessary as people got familiar with each other through the conversation. Without understanding the rationale that those who are DHH are perceiving conversations (through interpreters or captions) that do not afford familiarity over time, he was not consistently executing the norm in an effective way.

Recommendations: After reflecting on our experience, we discussed the ways in which norms could have been communicated more clearly and effectively. First, a list grouped by accommodation *context* rather than disability can make the accommodations more actionable. For example, our accommodations this summer could have been grouped into “conversational norms” and “slide deck norms.” Relatedly, updates to the list should be announced in synchronous meetings, if possible, to ensure that the community is aware of new changes. Second, to avoid assuming background knowledge of meeting attendees, group members can make a concise list of basic accessibility background for the disabilities present in the group (e.g., what is a visual interpreter), with links to more detailed resources. This list may benefit existing group members, new group members (e.g., interns), and short-term guests to the community (e.g., guest speakers). When there is a large group of new community members, like a group of interns, going over this information synchronously can help ensure understanding, while also establishing accessibility as an important group value.

Norm Execution and Accountability

There were three main aspects of our summer meetings that affected the norm execution and accountability. First, as the list of accommodations grew, *it became harder and more time consuming* for team members to ensure that they followed each accommodation listed. Particularly for conversational norms, team members found it challenging to remember to follow the accommodations every time they spoke. The real-time nature of live meetings does not easily support multitasking (i.e. engaging with accessibility guidelines and conversation simultaneously), or allow much time for corrections.

Second, accommodations were *implemented only when the person who the group viewed as* *needing the accommodations was present*. For example, Das noticed that the norms were followed less strictly in intern lunch meetings where disabled interns were not present than in larger team meetings. Only using norms in the presence of perceived disabled interns makes it difficult to accommodate everyone, in particular people with undisclosed, invisible disabilities [Faucett et al., 2017, Cory, 2005]. Additionally, this process led to norms being applied intermittently, which makes it harder for new norms to become habitual.

Finally, we had no established method for correcting people when they failed to follow norms. In a group where members had a wide range of seniority levels, it became uncomfortable for those with less power to correct those with more power [Bennett et al., 2018, Das et al., 2019].

Recommendations: We identify social and technology based interventions that can improve norm execution and accountability. First, teams can apply community norms during all team meetings, regardless of who attends. Consistent application helps habituate behaviors and allows disabled participants to experience their accommodations without needing to disclose their disability status. Second, the community can establish norms around how to correct people who break a norm (perhaps with an anonymous option), which may mitigate tensions due to power differentials.

Finally, we acknowledge the space for technical contributions in upholding access norms in a virtual setting. Our accessibility failures were partly due to the difficulty of the problem; remembering different needs in different settings is challenging. Therefore, technologically prompted reminders of norms (e.g., Microsoft Teams prompting: “did you introduce yourself before speaking?”) may improve adherence. At the same time, a system that does this task well can shift the access labor from group members with disabilities or their allies to itself.

5.6.2 Invisibility

We discuss the challenges that were introduced in a fully virtual setting due to the invisibility of access labor, accommodations, and the effects of inaccessibilities in remote settings.

The access labor that people performed tended to be hidden [Branham and Kane, 2015a, Shinohara et al., 2021] in the virtual setting, making it challenging for allies and team members to understand the scope of the accommodations. For example, team members were unaware of the complex set up required to receive captions, which also splits the caption user’s attention. This considerable access labor in a virtual setting led to Jain's hesitation to join company-wide intern events, while his allies were unaware that his lack of attendance was due to access challenges. More generally, allies for people with disabilities may have a harder time sharing in the access labor when they are not co-located with the person with a disability.

Similarly, the effects of inaccessibilities could be easily hidden from other team members in virtual settings. In an extreme example, Mack would turn her camera off if she became ill from her motion sickness being triggered on video calls. Relatedly, Potluri silently left a meeting due to feeling overwhelmed from too many audio streams. The hidden nature of many of the consequences of inaccessibilities made it more challenging for allies to identify inaccessible situations. Consequently, allyship was forced to be more proactive in virtual settings. For example, after hearing Mack's situation, Yamagami was proactive in reaching out to Mack to provide support.

Finally, the virtual setting made the distinction of accommodations and who received them murky, particularly in the case of ASL interpreters. Because interpreters were unlinked, Park, Das, and Davis commented that they were unclear of the interpreter's role (i.e., not a team member) and who the interpreter was interpreting for. Tang noted this was especially confusing when the perceived gender of the interpreter for one colleague changed mid-meeting.

Recommendations: Because the virtual context makes key aspects of disability and accessibility hidden, we suggest a few tips for allies to help improve accessibility. First, we suggest creating ways of making access needs and accommodation use more explicit in virtual settings. For example, this may include developing methods for linking interpreters or other accessibility support members to the person they work with. Additionally, when a person is using an interpreter, participants sharing their name before their thoughts can help reinforce this connection to who is communicating, which is helpful in large groups [Kushalnagar and Vogler, 2020]. From a more high-tech perspective, an ideal solution would be for an interpreter's voice to be linked to the Deaf signer's video. Second, disabled members may explain how they would prefer to engage in meetings, if they are comfortable doing so. For example, Jain could explain his complex setup or state "if you need to reach out to me, reach out via a text message." Ideally, as video conferencing platforms evolve, they should build accessibility features into the platform, thus decreasing the access burden for the disabled participant.

Allyship also became more difficult in a virtual setting due to the invisibility of access labor and the effects of inaccessibilities in virtual meetings. We suggest that allies take a proactive approach in providing support [Hadley, 2020], without being overbearing. Unprompted access check-in's may be appreciated. These check-ins may be even more critical for mentors/managers to do with their mentees, as our experiences highlight the natural team and power dynamics that may make it more difficult for interns to share access issues with their managers.

Additionally, our work demonstrated a new communication channel available to allies because of the virtual setting: text back-channeling. This affordance may allow for more effective allyship in some cases. For example, Bragg felt a tension around when she should speak up for her mentee. An established back-channel could allow her to ask her intern with a disability if he wants her to speak up instead of assuming that help is needed [Hofmann et al., 2020]. On the other hand, use of back-channels for allyship has the disadvantage of making ally work invisible. Team members should initiate conversations around if and when it is appropriate to make accessibility issues and/or allyship visible.

5.6.3 Limitations

We acknowledge that, with our selection of autoethnography as our method, the generalizability of our method is inherently limited. No team will likely have the exact configuration of access needs and work responsibilities as ours did this summer. However, the issues that we face are more widely experienced than just by our team. For example, prior research also describes access conflicts [Hofmann et al., 2020]. Our work exemplifies how these issues can arise and affect a team, and our recommendations steer people and technology towards collectively, respectfully resolving conflicts and other hard situations. Further, our team was working at a US-based company, well-resourced company where team members were highly skilled in using computers. Other teams that have more varied levels of technological expertise or resources to provide access will likely have more different experiences from our own. Finally, from the start, our team had a strong commitment to accessibility, which is one of the critical components (and hardest to acquire) when trying to make teamwork accessible. We encourage future research to explore methods for increasing commitment to providing accessible experiences for all team members on teams where it is lacking.

5.7 Conclusions

Due to the pandemic, our team at Microsoft Research experienced a fully virtual internship on a team with mixed abilities. Through our autoethnography, we share our rich, personal experiences and discuss the key features that combined in unique ways to shape the accessibility of our team: virtually induced (in)accessibility, power dynamics, remembering lengthy and conflicting accommodations, and allyship. **Taken together, our experiences demonstrate how multiple people's access needs interacting and a virtual context shaped what our accommodations looked like for the summer.** Finally, we reflect on practices around community norm formation and the invisibility of disability and access labor, commenting both on successful and unsuccessful approaches. We note that there are several opportunities for technology to support the accessibility of virtual teams. Particularly as video calling and conferencing software are evolving rapidly now, we ask platforms to build with accessibility in mind, and for scripted plugins to allow for more customizable accessibility features.

Chapter 6

“IT’S LIKE GOLDILOCKS:” BESPOKE SLIDES FOR FLUCTUATING AUDIENCE ACCESS NEEDS

This chapter is based on this publication (screen reader accessible).

6.1 Introduction

Slide decks are common in both work and school settings for making presentations to share information with a group, class, or organization. For the millions of people who have disabilities, there are several factors that can makes slide decks more or less accessible, given their abilities. However, disabilities vary so vastly that the access needs of different individuals can look starkly different, or even conflict with each other [Hofmann et al., 2020, Mack et al., 2021b, Mack et al., 2022a]. More-over, a single person’s abilities can vary drastically throughout the day, and impact what access needs they have when consuming slide decks in a specific context [Mack et al., 2022b]. **As slide decks presentations are often delivered in group settings, they offer an ideal case to understand how the differences in abilities between people, differences in abilities for a single person, and different social and spatial contexts can impact access needs and access provisioning.** In this paper, we investigate slide deck access needs for people with a wide variety of disabilities. Then, we design and test a system that adjusts a user’s local copy of a slide deck to meet their access needs in-the-moment, and we test the system in a presentation setting to demonstrate its utility.

Prior research has investigated how people who are blind and visually impaired (BVI) can con-sume and present slides [Mack et al., 2021a, Peng et al., 2022, Peng et al., 2023] and how to improve caption-users’ experience consuming presentations [Yip et al., 2021]. However, this re-search largely focuses on the access needs of people who are BVI, though there are a number of disabilities and related conditions that can impact the ability to consume slide decks, like chronic illnesses and neurodivergence. Additionally, there exist lists of best practices for how to make slide decks more accessible generally (e.g., having highly contrasting text and background color, and large fonts) [DO-IT, 2022, University of Colorado Boulder Digital Accessibility Office, 2024, Mi-crosoft, 2024c]. These checklists often suggest making a single round of changes to a slide deck that will make them "accessible." However, with this paper, we demonstrate that a single one-size-fits-all slide deck cannot meet all access needs at once. Instead, **we imagine a future where slide decks can adapt to meet individual user needs in the moment.**

We conducted focus groups and interviews with 17 individuals with a diverse range of accessibility needs, including people who identify as disabled, as having chronic illnesses or mental health conditions, or as neurodivergent. They shared their current concerns with slide deck accessibility and what characteristics their ideal slide decks would have, recognizing that one person might have different preferences or needs in different contexts. We found that access needs around slide decks vary drastically between different individuals, and that they can change drastically for a single person throughout the day. We then invited participants back for a second session where we used a design probe to test the impacts and feasibility of using a more accessible, customized slide deck during a presentation. A member of the research team presented a preexisting presentation while participants followed along with their own custom copy of the slide deck. We created these customized decks based off the characteristics each individual preferred in the first study session, and participants subsequently provided feedback on their experience with these decks. We found that customized slides could remove accessibility barriers for participants, but that they also added cognitive and logistical overhead that needs to be considered when designing slide customization tools. Finally, we conducted four interviews with authors and presenters of slide decks to offer a complementary perspective and understand the concerns they might have with a system that automatically changes their slides to improve access.

Finally, we implemented a proof-of-concept system that could carry out such accessibility-focused customizations to slide decks on-demand. Beyond demonstrating the feasibility of the system, this process allowed us to highlight what features are possible to implement with existing application programming interfaces (APIs) for popular slide deck software and which would require more sophisticated logic (e.g., optimization algorithms) or integration with external services (e.g., computer vision pipelines). Further, we document what properties and functionality an API must expose for someone to be able to build an accessibility-focused slide deck customization tool, noting that popular softwares' APIs do *not* support all necessary functionality at the time of this publication.

In summary, this paper contributes: 1) a characterization of a wide variety of slide deck access needs of people with different disabilities, 2) insights into how having different, customized copies of slide decks in use at once impacts a presentation environment, 3) a list of API capabilities that are required to fully support accessibility-focused slide deck customization tools.

With respect to the broader dissertation, this chapter identifies one final factor to consider in designing technologies to meet access needs in group contexts: differences between group members' abilities. What was accessible for one participant in this study was often inaccessible to another. Notably, the testimony of participants demonstrates that all of the previously identified factors in this dissertation impacted participants' experiences consuming slide decks (variation in individual ability, social context, spatial context, visibility of disability). Through analyzing their interview data, we enumerated key facets of slide decks that must be customizable to allow for a more accessible experience with slides. These factors informed the design of our final tool in this chapter, and could be adopted by popular authoring tools today to improve accessibility for a wider variety of people with disabilities. Finally, in this chapter we demonstrate how to design and develop a system considering all five factors that can impact group accessibility identified in this dissertation.

6.2 Related Work

Here, we summarize the work done by researchers and technology companies to study and create more accessible slide decks. In short, slide deck accessibility has been thoroughly studied from the perspective of improving access for BVI people [Peng et al., 2021b, Peng et al., 2021a, Peng et al., 2022, Peng et al., 2023], but little work has investigated the access needs of other communities [Yip et al., 2021]. We conclude by discussing existing work in interface adaptation for access and non-accesss purposes [Gajos and Weld, 2004, Gajos et al., 2008, Gajos et al., 2007, Jain et al., 2022, Goodman et al., 2021, Mott and Wobbrock, 2019, Mott et al., 2016], as in this work we design a tool that automatically adapts slide decks to meet the access needs of each individual.

6.2.1 Slide Deck Accessibility

Several professional organizations (e.g., Microsoft [Microsoft, 2024c], universities [DO-IT, 2022, University of Colorado Boulder Digital Accessibility Office, 2024]) have curated lists of best practices around slide deck and presentation accessibility. Combined, these suggestions include having sufficient color contrast between all slide elements, ensuring all text is sufficiently large, including alt text with all images, using unique slide titles, and limiting the amount of content on a slide. Tools that help to ensure slides uphold these guidelines (GrackleDocs for Google Slides [Grackle, 2024] and Microsoft's Accessibility Checker [Microsoft, 2024b] for PowerPoint) typically identify issues such as poor contrast, missing alt text, non-unique or missing slide titles, and slides that might have nonsensical reading orders[1]. These tools most often focus on identification of issues and rely on users having the knowledge, motivation, and skill to repair the issues. Though, in one of the few counterexamples, Microsoft provides AI-generated alt text for images [Microsoft, 2024a]. Microsoft also has developed interfaces to improve user understanding of how to write useful alt text [Mack et al., 2021a, Microsoft, 2024a].

Other work has studied how to improve slide deck accessibility, almost exclusively focused on accessibility for BVI individuals. Peng et al. investigated how to improve BVI slide deck consumption accessibility from several perspectives. From a presenter perspective, they built a tool that identifies when presenters fail to fully verbally describe all slide elements via real-time feedback [Peng et al., 2021b]. In the context of reviewing recordings of presentations, Slidecho allows access to the visual information in real-time while watching the video, without requiring access to a digital copy of the slide deck [Peng et al., 2021a]. Turning to authoring and navigating local copies of slide decks, research explored how to better allow BVI people to access details of visual design in slide decks while authoring with sighted individuals [Peng et al., 2022] and how machine learning techniques can create a better way to navigate slides through a novel hierarchical drill-down approach [Peng et al., 2023]. Zhang et al.'s A11yBoard focuses on providing a better experience for consuming and authoring slide decks, especially in the slide designer pane [Zhang et al., 2023].

A few other studies have focused on slide deck accessibility for other communities with access needs. For example, Cavender et al. studied how to manage the numerous different demands on d/Deaf and hard of hearing (DHH) students' visual attention. [Cavender et al., 2009]. Brandão et al. created a tool that allows for better pacing while delivering slide presentations in educational contexts when interpreters are present [Brandão et al., 2016]. The study we present in this paper expands prior work to consider slide accessibility beyond BVI and DHH people's access needs,

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[1] Reading order refers to the order that a screen reader would encounter the items on a slide

including people who have chronic or mental health conditions and people who are neurodivergent. The access needs of these groups have been underrepresented in prior work but, we argue, are feasible to meet with slide deck customization capabilities.

6.2.2 Customizable Interfaces

Past research has identified the need for technologies to be responsive and customizable for disabled users [Wobbrock et al., 2011]. For example, Gajos et al. demonstrated how a system, SUPPLE, can make customized interfaces specifically for disabled users' needs [Gajos et al., 2008, Gajos et al., 2007]. Other work investigated how to tailor menu interactions [Bailly et al., 2013] to best meet user needs, or how to customize sound recognition tools for d/Deaf or hard of hearing individuals [Jain et al., 2022, Goodman et al., 2021]. Other work in this space focuses on touch-based interactions for people with non-normative abilities, including people with disabilities [Mott and Wobbrock, 2019, Mott et al., 2016], older adults [Findlater and Zhang, 2020], and children [Vatavu et al., 2015]. For example, Mott et al. investigated how to improve interactions for people with mobility disabilities on touch screens through development of a system that can accurately sense a user's intended touch target even if multiple points of touch occur on a screen (e.g, with the side of a hand), using machine learning techniques [Mott and Wobbrock, 2019]. Most work in this area has focused on adapting to meet access needs within a single disability. We extend these concepts to support multiple disabled people in the context of live presentations, and further, we explore the social consequences of using customized tools during group conversations. Specifically, we enumerate properties of slide decks that were critical for people with diverse abilities to be able to customize to meet their access needs, which prior customization and slide deck research does not investigate.

6.3 User Study Method

To understand slide deck accessibility needs and inform tool design, we conducted a three-phase user study with presenter and audience member participants. In the first phase, we conducted focus groups with *presentation audience members* about what makes slide decks particularly (in)accessible. In the second phase, we invited the same participants to a technology probe [Hutchinson et al., 2003], where a member of the research team presented a slide deck while participants followed along with a customized, accessible copy of the slides, which we designed and created for them. Finally, in the third phase, we interviewed a small number of *slide deck authors and presenters* about their feelings towards the types of changes our proposed tool was making to their slides. This multi-phase study produced a list of priorities from audience members and presenters for making accessibility-focused changes to slides, which we used to inform the design of our system described in section 6.6.

We recruited audience members who had slide deck-related access needs through mailing lists, group messaging forums, and by reaching out to our personal networks. Most participants identified as having a disability, chronic or mental health condition, or as neurodivergent (see Table 6.1). We recruited slide deck authors and presenters through university messaging forums and selected people who gave presentations regularly, in both professional and classroom contexts. Audience members were compensated $40 for the focus group session and $40 for the presentation session. Presenters were compensated $40 for their interview. This study was approved by out institution's IRB. We sent participants an information form before the study and encouraged them to ask any questions they had.

6.3.1 Phase 1: Audience Member Interviews

We began by conducting focus groups with 17 audience member participants, whose demographic information is summarized in Table 6.1; their average age was 27 (range 20-39). In these sessions, we first asked about general slide use at school or work, including in what contexts they use a personal copy of the slides (e.g., before, during, or after a presentation). We then focused on what features of slides made them more or less accessible for each participant. Once this discussion concluded, we informed the participants of our intent to create custom slides for all participants for the second study session. If it was useful for participants and time allowed, we used a slide deck to demonstrate different features of slides that could be customized to meet their needs, including font size, font family, font spacing, font color, background color, amount of whitespace, creating room on slides for captions, and using slide templates. We selected these features based on common best practices for slideshows[Microsoft, 2024c, DO-IT, 2022, University of Colorado Boulder Digital

Accessibility Office, 2024]. We then asked participants to fill out a form with open-ended questions to specify what aspects they would like their ideal slide deck to include, encouraging them to list anything they could think of without worrying about real-world constraints. If participants had different preferences for slides used for reviewing slide decks before or after the presentation and used during a presentation, we asked them to fill the form out multiple times. In total, participants requested 12 different decks to use during presentations, 6 to be used for review before or after the presentation, and 2 to be used in both contexts[2]. The properties that participants requested of these decks are listed in Table 6.2. Three title slides with examples of the types of changes participants requested are shown in Figure 6.1.

We were committed to being inclusive in our study sessions. Consequently, we provided several accommodations, including sending questions ahead of time, making sure that our slides were not painful or disorienting (e.g., making slides in dark mode or light mode upon request), and using automatic captions. Some participants had work or childcare constraints that prohibited them from joining us during our focus group sessions, so we offered solo interviews to these participants, and four participants participated this way. Interviewees answered the same set of questions as focus group participants. In total, we ran six focus group sessions and four interviews.

6.3.2 Phase 2: Presentation Session

For the second phase of our user study, we conducted a technology probe to understand the impacts and feasibility of each audience member having a customized slide deck in use during a live presentation. To do so, we selected a research assistant to be our presenter across three presentation study sessions, all of which were run identically. She shared several slide decks with the research team that would each take 10 minutes to present. We selected the one that demonstrated the most common issues that participants discussed in phase one of the study. This deck presented the results of a research project done by the presenter about how d/Deaf and hard of hearing individuals communicate in groups. The deck had 19 slides and used one of the default Google Slides templates: “pop,” (see Figure 6.2). We added one slide to the deck that introduced a collaborative activity (think, pair, share [Kaddoura, 2013]) for audience members to perform with another session participant. Dis-

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[2] Note this sums to more than 17 because some participants requested multiple decks.

Gender	
Woman	8
Man	4
Nonbinary	2
Trans masculine	1
Nonbinary, agender, genderqueer, genderless, trans	1
agender/nonbinary	1

Race	
White	9
Asian	5
Latina	2
Middle Eastern	1
East Asian	1
Mixed/multiple races	3
Prefer not to respond	1

Disability or related condition	
Neurodivergent	8
Chronic illness or condition	6
Blind or visual disability	6
Mental health condition	3
Brain injury	1
Deaf	1
Physical disability	1
Psychosocial disability	1
Multiple disabilities	10

Table 6.1: The demographics of our 17 audience member participants, including their self-reported races, genders, and disabilities or related identities.

Property Requested	# Participant Requests
Font and/or background color	15
Amount of content per slide	13
Font family preferences	8
Font size preferences	7
Color contrast preferences	6
Specific spacing between words or paragraphs	6
Space for captions	4
Use of slide templates	4
Text document instead of slides	3

Table 6.2: The properties that our participants requested for their personalized versions of the presenter's deck to be used in phase 2 of the study.

cussing with peers after attending a talk is a common aspect of presentations, and we wanted to see the impact of different versions of slide decks in this context.

To prepare for the presentation session, a member of the research team created custom copies of the slide deck that were customized for each participant based on their responses from Phase 1. We sent these customized slides to each participant along with the original presenter's deck to allow participants to compare them if desired. Thus, participants had a copy of custom slides that they could 1) follow along with during the study session or 2) use to review the slides before or after the presentation.

The virtual presentation session was held on Zoom and 14 of the 17 participants from Phase 1 of the study attended. We began with brief introductions and access norm setting, and then let the research assistant deliver her 10 minute presentation. At the end of the presentation session, she introduced the think, pair, share activity and we let participants discuss in pairs in breakout rooms. We then transitioned into a reflection period where were encouraged participants to share with the group about what it was like to use their custom slides during the presentation and sharing activity. The presenter left for this phase of the session so that participants would feel more comfortable critiquing her slide deck.

Finally, we concluded by asking participants to fill out a 10-15 minute survey that asked mainly open-ended questions about 1) the effectiveness of their custom deck during the presentation session, 2) their experience talking with fellow audience members who did not have the same slides, 3) how effective a custom deck specifically made for reviewing before or after a presentation was (if applicable), 4) their likelihood of using their custom deck inside or outside of the presentation, and 5) if they would make any further changes to their custom decks.

6.3.3 Phase 3: Presenter Interviews

We recognized that if a tool existed that made substantial changes to slide decks to be more accessible to each audience member, it might result in substantial changes to the presented slides. Therefore, we concluded our user study by interviewing four people with experience presenting slides in classroom or professional contexts about how it would feel to know such a tool was being used during their presentation. When participants signed up to participate, we asked them to share a deck with us that they had presented in the past. We then produced two new versions of these slides. To each custom deck, we applied one set of the most common changes requested by participants. The changes we made were as follows:

Deck 1: a version of the deck where we changed all text to a specific font family and changed the slide colors to a dark grey background with white text.

Deck 2: a version of the deck where we enlarged all text, which sometimes required splitting a slide in two, and we summarized large chunks of text.

We asked participants to discuss if there were any changes that they were opposed to, whether because they distorted the presenter's original message and content or because of other reasons such as intentional aesthetic design choices.

6.3.4 Analysis

We performed reflexive thematic analysis to analyze the results from our focus groups, interviews, and open-response survey data [Braun and Clarke, 2006, Braun and Clarke, 2019]. Two authors divided up and read all of the transcripts from our focus groups in Phase 1 of our study. They identified codes and broader themes, which they discussed in weekly meetings. They worked together to agree on a final set of codes for the codebook, which one author then applied to all transcripts. The same author then repeated a similar process for the data from Phase 2 (presentation session) and Phase 3 (presenter interviews) of the study: the author reviewed each transcript once to identify codes, solidified the codebook, and then applied the codes on a separate pass. We used codes from prior phases' codebooks (e.g., Phase 1's codebook) if they applied to data from other parts (which occurred frequently). Combined, our codebooks had 129 codes, and top level themes included topics like "features of accessible slides" and "coping mechanisms for dealing with inaccessible slides."

6.4 Study Results

Participants used slides in diverse contexts and formats. Most often, they used slides in work or school contexts, but sometimes used them for student groups or church. While they most often consumed slide decks on computers, they sometimes used phones, tablets, or physical print-outs of slides, depending on personal preference and context. We now dive into the accessibility of slide decks and slide presentations for participants with a wide range of disabilities. Specifically, we discuss 1) how people engaged with slides at different times for accessibility and non-accessibility purposes, 2) what elements of slides are particularly accessible or inaccessible to slide consumers, and 3) how presenters' actions could impact slide deck accessibility. Audience member participants are denoted with A#, and presenter participants are denoted with P#.

6.4.1 Different Kinds of Engagement with Slides

Almost all participants preferred to engage with their own copy of the slide decks before, during, or after the delivery of the presentation.

Before and after presentations: Accessing slides before presentations allowed participants to preview information and therefore feel less overwhelmed during presentations. Participants who had disabilities that affected their ability to read and process visual information found information-dense slides overwhelming (A1, A5). Reviewing slides ahead of time allowed participants to start pre-processing and enter the presentation with a "basic mental framework" of the concepts (A2). After presentations, many participants described reviewing information (e.g., for a test or lab assignment) or reading content that they missed during the lecture because they "tuned out."

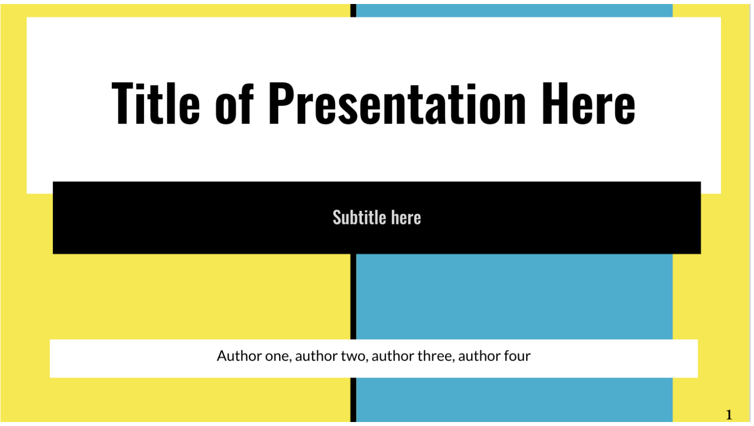
During presentations: Some participants followed along with a copy of the slide decks on their own device during lectures, often to take notes or to make things more accessible for themselves. For example, A8, who is blind, used slides at work and had to read part of a dialogue aloud. Having her own copy of the slides enabled her to know what she needed to say and when. A13, who is Deaf, found that he could align his laptop with the slides open near the speaker, allowing him to receive all visual information sources in one line of sight.

Finally, several participants used their own copy of the decks to better control the pacing and layout of slides, as A16 explained: *"[I like having my own copy so that] I can control exactly how big it is, [and] I can move the slides as fast or slow as I want them."* Several participants appreciated the ability to preview the content coming up next or to go back and review content that they did not understand or missed. A14, who is neurodivergent, described how having a personal copy of the slides allowed them to manage their attention for a class. Sometimes they would lose focus during an important part of the presentation, and the slides let them review what they missed and tune back in. At the same time, previewing the slides allowed them to purposefully zone out when they needed a break: *"Knowing: 'oh, okay, we're about to go talk about t-test ... I can do those in my sleep, whatever. Let me zone out for a couple of slides."'* Thus, having the slide deck allowed A14 to both regain focus when distracted and budget where to pay attention.

However, some participants found that following along with slides was too distracting to be useful. For screen reader users, it was overwhelming to listen to the professor and screen reader audio at once: *"there's also the screen reader [audio,] and then there's also the professor talking, and simultaneously, I'm also trying to take some notes,"* which is a lot to process at once (A4). Some neurodivergent participants preferred not to use devices during presentations to avoid distractions: *"having a version that's maybe like cleaner wouldn't be enough of an incentive for me to want my own version, because then I would have it pulled up on my computer. And then I would, you know, start checking other tabs. The next thing I know, I'm just not listening at all"* (A7). While following along with a personal copy of slides was an accessibility boon for some people, it was a distraction for others.

6.4.2 Factors of Slides that Impact Accessibility

In Table 6.3 we list some of the features of slides that participants found to be accessible and help them during a presentation.



Title of Presentation Here

Subtitle here

Author one, author two, author three, author four

1

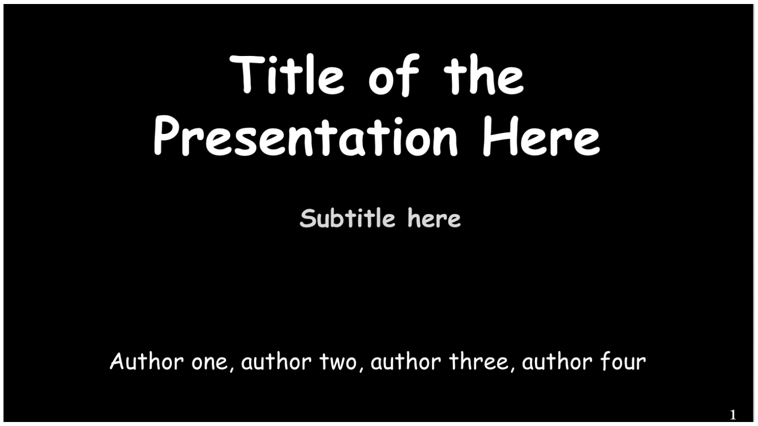
(a) The author’s original title slide template.

Title of Presentation Here

Subtitle here

Author one, author two, author three, author four

(b) An example of a participant-requested version of the title slide that uses Times New Roman font family, and black text on a white background.



Title of the
Presentation Here

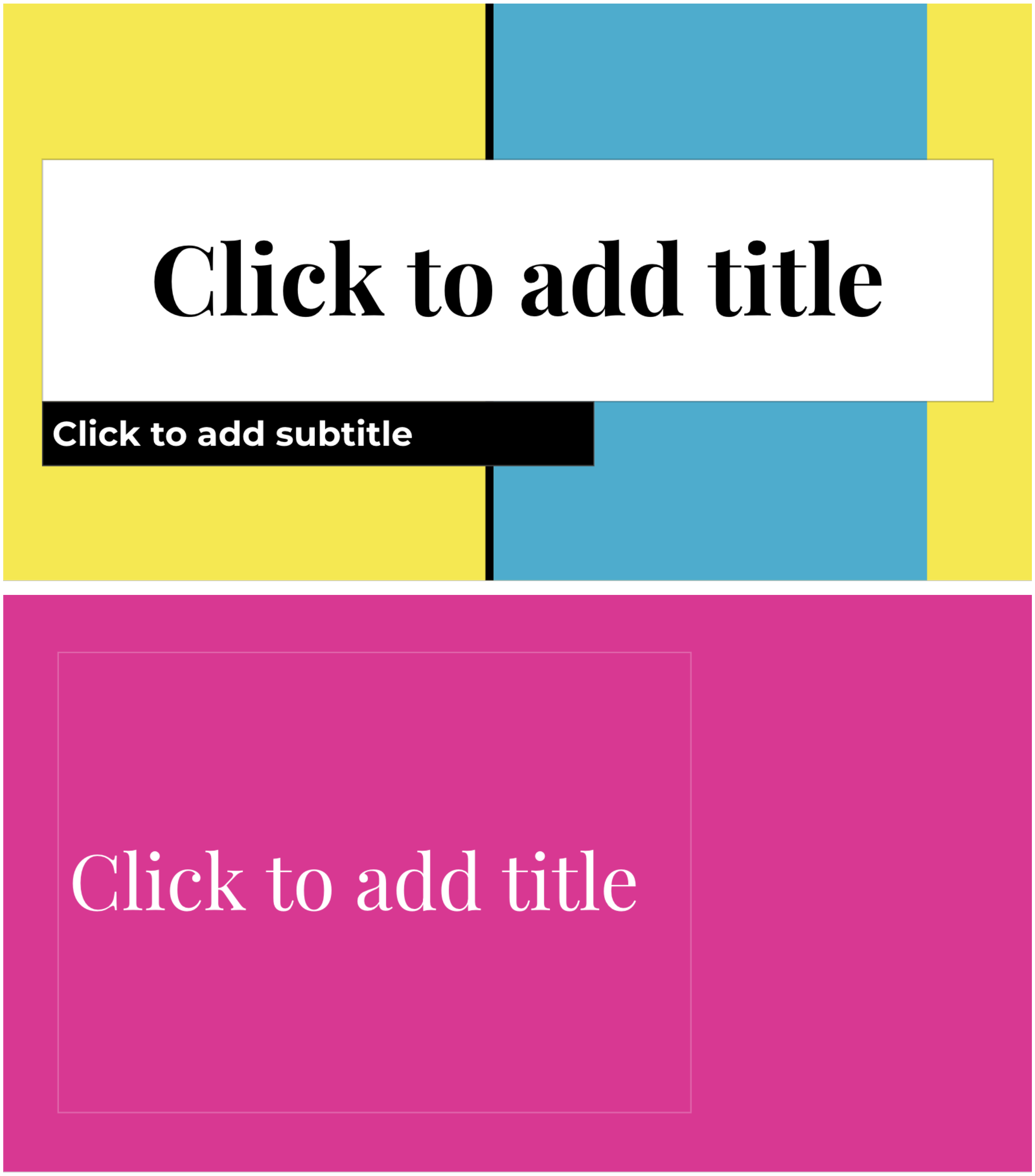
Subtitle here

Author one, author two, author three, author four

1

(c) An example of a participant-requested version of the title slide that uses Comic Sans font family, white text, a black background, and a higher minimum font size.

Figure 6.1: The original title slide template that our research assistant as well as two example variations that our participants requested.



Click to add title

Click to add subtitle

Click to add title

Figure 6.2: Two screenshots of the template used by our presenter. It includes decorative, serif fonts and brightly colored section slides, each of which can cause accessibility issues.

Table 6.3: These are different characteristics of slide decks that different participants found to be *more accessible* for them *during slide deck presentations*.

Feature	Feature Spec.	Problem Addressed	Quote
Font size	Larger font size	Hard for people with low vision to read	"if [the font size is] not bigger [and] it's a very wordy slide, I find it very hard to like read."
	Smaller font size	Hard to follow along with large fonts when slides must change frequently	"I actually can't handle such large print, either, that it fills the whole page."
Font family	Simple font	Some complex fonts with extra decoration are hard to read	"If they use something italicized and a very wonky text. I find it very difficult to like focus"
	Dyslexia friendly font	Some fonts are more readable to people with dyslexia or neurodivergence	"Open Dyslexic is my favorite font, or comic sans."
	Multiple fonts	Helps maintain reader's attention	"Changing fonts ... would keep me more engaged. My brain would more likely find this interesting..."
Colors	Color blind friendly colors	People who are color-blind cannot always discern if something is denoted only by color	"[Presenters] like to change text to red as like a way of highlighting... I can't see it at all half the time, because there's no other indication"
	Colorful slide backgrounds	Helped keep attention for some participants	"I found the color a lot more engaging."

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Table 6.3 – continued from previous page

Feature	Request	Problem Addressed	Quote
	Neutral slide backgrounds	Bright colors could hurt people’s eyes and be distracting	“Oh, my God! The yellow color! What the fuck! Ow!”
	Dark slide backgrounds	Some people get migraines from bright light	“I’m actually avoiding some of the colors on the screen, because ... then I’ll have a migraine for the rest of the day,”
	Low contrast	Pain from too highly contrasting colors, especially with blue-light-heavy displays	“Yeah, too high [contrast] can be almost painful.”
	High contrast	Too hard to read the content on the slides	“If I’m all the way in the back of the room, it can be a bit of a challenge, and it gets worse, particularly in rooms where there are like overhead [lights]...”
Images	Concise, complete alt text	Enables people who are BVI to understand why images are included in decks	“[I want] detailed enough, but not super long to make me on focus from the main point”
	High quality, large images	Low quality images can be hard to see	“I have a harder time with images. Again, they are blurry”
	More images	Helps some people learn and remember better than text	“I can picture keywords with visuals better than text.”
	Fewer decorative images	Images can distract from the main content of the talk	“If you’re presenting on a content, that the pictures are not relatable to, that’s kind of distracting from me”

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Table 6.3 – continued from previous page

Feature	Request	Problem Addressed	Quote
Content Understan - dability	Replacing jargon/acronyms	Acronyms and jargon can be hard to follow, especially for people with cognitive disabilities	“It would be nice to kind of have that simplified version as well ... I’m taking [machine learning] right now, and sometimes the slides are super technical.”
	Have less text per slide	People get overwhelmed when they see a lot of text on a slide	“I’m not really paying attention anymore, because I’m just like: ‘oh, my God, how am I gonna get all this information while they’re talking.”’
	Whitespace and linespacing	People preferred more text linespace and more spacing between slide elements	“The spacing between [bullet points] is also important in helping me distinguish them, especially if those bullet points end up spanning multiple lines.”
	Summarizing main takeaways	Helps people follow along and provides more context if main points are clearly indicated	“But having just the main takeaways like in bold or underlined ... I’ll get very caught up with all the little details of connecting everything together, and it really like draws me away from the big picture.”
Nonvisual access	Proper tab order[3]	When the tab order is incorrect, people get confused or have a hard time following	“You’re having to keep track of. Okay. I was going from this, and I got go through these 5 other things to get to the other column and then go down to the third space in column 2, and try and remember what it corresponded to in the third space in column one.”’

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Table 6.3 – continued from previous page

Feature	Request	Problem Addressed	Quote
	Slide numbers	Help people keep pace with presenter	“A lot of times teachers will switch slides and you have no clue until they refers to something that’s very obviously in slide eight. And then you’re like, ‘Okay, I guess we’re not on six anymore”’
	Other Document Formats	Converting the slide deck to an accessible text document can be more accessible for people using screen readers	“Maybe not have slides at all and have it in a document ... I’m able to navigate as I need. ”
Other	Use no or simple animations	Animations are distracting	“I’m looking at every single thing that’s moving, and I get taken away. And my my focus is lost.”
	Use content warnings	When content is potentially triggering, a warning helps students prepare or opt out of hearing the content	“If someone include something that I find very like triggering or upsetting, or like emotionally upsetting ... put a content warning on”

Participants emphasized the importance of having their own needs met and how powerless they can be to do so in the current slide show paradigm: *“Physically I don’t have control over people’s slides. So you kind of just have to deal with it. My ophthalmologist gave me [special] glasses . . . Those are probably the only measures I can take for my own [wellness]”* (A6). At the same time , it is clear that a *single* deck cannot meet all of these needs, as many of these requests conflict (e.g.,

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[3] Tab order determines what order a screen reader will traverse the elements in a document.

preference for lower and higher contrast, as seen in Table 6.3). We now explore some of the reasons why these differences in preferences and needs arise.

Differences between people

Access needs related to slide decks varied drastically between different people. A9 and A7 found colorful slides to be distracting because of their disabilities, while others found the bright colored slides painful (A6, A16), and still others found brightly colored slides incredibly helpful in terms of maintaining their attention (A15, A17). Participants respected that other people in their focus groups had different preferences for "equally valid reasons" (A9), and were excited by this proposed tool as a way to meet conflicting needs.

Differences for one person over time

For some participants, accessibility preferences changed as their symptoms or abilities changed or as their environment changed. A2 discussed the multitude of factors that impact her access needs: *"It's hard to pin this down [what contrast level I need at the moment], because [it] depends on where I am in a [menstrual] cycle, how much I've been reading, what the ambient light in the room is, what the slide design is."'* A1 faced similar issues with contrast, where his preference varied based on the severity of his eye fatigue and symptoms: *"I guess it's a little more like Goldilocks, where I need that sweet spot more and more."* For A1 and A2, individual factors impact visual processing, which can make it near-impossible for them to accurately predict exactly what contrast level they would need before any given presentation.

Differences between contexts

Context and manner of consumption of slides similarly impacted what was most accessible for participants. Slide decks often serve one of two purposes: sometimes they are intended to be delivered during a presentation, and other times they serve as a standalone resource for sharing information in a class or company. Consistently, most participants preferred having a slide with fewer words during the presentation, but preferred a much more verbose deck that offered more context to the content if they were reviewing it outside of the presentation session: *"[If the] presenter ... [is] using* *very few bullets on their slide, that's great for not having an overwhelming slide, but then I am having a harder time understanding what the slide is about [later]"* (A1). Several other participants also commented on the fact that many presenters who present sparse slides added a large amount of additional context with their voiced or signed[4] content, and slides were often difficult to understand without this context. Specifically, people wanted decks for reviewing outside the presentation session to clearly present the main point of each slide.

Two people who identified as neurodivergent followed along with printed versions of slide decks during the presentation, and the format they consumed the slides in impacted what features they wanted to prioritize in the slides. A16 explained: *"I don't like super high contrast [in a digital context] because that can be painful. But in print, it does need to be higher contrast. But the background that it's printed on can't be so bright that it hurts."* A16 needed to balance content clarity after being printed out on paper with their eyes' sensitivity to contrast. In the end, they chose to have the slide deck be high contrast for printing, but print it onto a cream paper to soften the contrast.

Finally, though people saw the benefits of having different slide decks for different contexts, they had reservations about the practicality of this paradigm. A9 described: *"I think, having 2 copies, while it would be helpful to see them both at the same time, ... that's just more things to keep track of, and I would be very prone to forgetting or like losing unless it was very systematized."* Another participant, A7, also commented that, in her day-to-day life, she often received decks in inconsistent formats (some via Google Slides, some via PowerPoints, some as PDFs), which might limit the scope of a tool remediates inaccessible slides, or at least increases its complexity.

Factors that influenced presentation accessibility beyond the slide deck

Finally, while not the main focus of our study, participants described several non-slide factors that impacted accessibility, including factors about how the presenter conveyed content and the presentation environment.

Presenter impacts: Timing was a concern for many participants, both in terms of how fast the presenter spoke as well as how fast they progressed through the slides. A5 is sighted and uses

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[4] Some people might present using a signed language like American Sign Language (ASL).

a screen reader to read most text, and they couldn't consume slides as quickly as the professor presented them. She raised the question: *"So, . . . where should I prioritize my attention to? Should I prioritize it to what the professor is saying? Or should I prioritize it to [the large amount of text] the professor told me to read and magically understand in 3 seconds. . . "* A5 found that presenters often did not balance the time it takes to read slides and how quickly they progressed through their presentations. Other screen reader users who were blind found that it was difficult to keep track of which slide the presenter was on, since so few announce slide changes. These experiences demonstrate that there is only so much support an accessible slide deck can provide; presenters will always shape the overall accessibility of a presentation.

Environmental impacts: Participants explained that factors of the environment, including lighting and distractions, impacted how accessible the presentation was. For participants who experienced blue-light sensitivity, the amount of blue-light that the projector in the room emitted was a key determinant of how easily (if at all) they could look at the slides being presented to the room for in-person presentations. Competing light sources in the room further impacted the clarity of projected content.

Other participants described that distractions, including other audience members, were the most disruptive part of the environment: *"if there is someone sitting in front of me, and they're tapping their pencil ... I will stare at the tapping pencil and like wish for it to stop so I can actually focus"* (A9). Other participants with sensory triggers similarly found that different presentation environments might make it harder for them to focus. Attending presentations virtually is one way that participants were able to successfully control these factors: Zoom mitigates several of the concerns discussed in this section, as it allows participants to use blue-light filters on their computer or minimize the distractions in their own environment (oftentimes at home). At the same time, other participants found virtual presentations to be *more* distracting, as they were distracted by their home environment and video calling platforms' chat feature.

6.4.3 Interactions with Presenters

While some participants found that presenters were responsive to accessibility requests relating to slide decks (A3), others experienced ableism or educational discrimination. A5's instructor for a college course withheld slides under the belief that it would stop students from attending lectures in person. A5, a screen reader user who needed the slides for access purposes, noted that when she asked professors for slides for access reasons, they were skeptical that she would only use them herself and not distribute them to her classmates. People, like A5, are demotivated to ask for accommodations because of this increased friction.

Participants' willingness to ask for remediation or accommodations depended on social dynamics and presenters' attitudes towards accessibility. A12 described how she would decide to bring up access issues or not: *"If there's a senior leader presenting, I might feel a little more hesitant [to] interrupt them in a big meeting, or [if] somebody is very ignorant about accessibility, I just give up due to the frustration."* In this case, the power dynamics and presenter's attitude toward accessibility could make A12 feel (un)comfortable askinging for accommodations in-the-moment. In other cases, a desire to not disrupt the presenter or other audience members caused participants to delay (or sometimes never seek out) access for presentations.

6.4.4 Presentation Session Results

In our presentation sessions, participants tested what it would feel like to use a custom slide deck with the changes they requested *in-situ*. Overall, participants preferred many of the changes they requested to their slides, though several changes needed further iteration (e.g., the font needed to be even larger). Similarly, the participants appreciated some aspects of the paradigm of having algorithmically-generated, customized slides, but also had reservations about its complexity and effectiveness.

Participants liked changes, but wanted to iterate further

Some changes that we made to slides based on participant requests were well received-and preferred to the presenter's original slides. For example, A7 appreciated having simpler slides for reviewing content outside a lecture, stating: *"I feel like I would actually use these to go back and study because they're very simple and I can easily find the slide I was looking for based on layout and pictures without being distracted by the colors of things."* In particular, people who experienced pain with bright colors relied heavily on their own copy of the slides or resorted to just listening: *"I didn't* *want to look back, because I found the original slides very jarring. So I just didn't wanna risk myself getting a migraine..."* (A15).

Other participants appreciated the idea of the changes they requested but needed to iterate on their execution. A6 requested dark-background slides to avoid migraines, but commented that they still wanted to maintain some of the "flavor" of the original slides. While we made their slides all the same dark grey background, regardless of the original slide color, they suggested, *"a monotone gradient color scheme, ... I do get ocular migraines, but I still want to feel the flavor of [the slides]."*

However, there were cases where people preferred the original slides over their customized copy. For example, A17, who is neurodivergent, requested slides with dark backgrounds rather than other colors. But, during the presentation, he found that the colorful slide backgrounds of the original presentation were more accessible for him because they better kept his focus. A17 also asked for reduced content on the slides. He found that sometimes the content that he was interested in (in this case, participant quotes), was removed from the deck, which will always be a risk for a tool that summarizes or reduces content. While not always perfect, most participants found the changes they requested resulted in more accessible slides.

Participants appreciated customization, but were concerned with complexity

Participants emphasized that they would want to use a customization tool themselves so that they could try different changes and see what worked for them. For example, A16 requested slides with a dark background, and we used a deep brown color. They found that: *"my synesthesia thought [the colors that I requested for the slides and text] are really gross, and I'm like, huh! . . . I wouldn't have possibly thought of that in advance."* Relatedly, such a tool could help participants better understand what slide accommodations could be useful for themselves. After hearing about other people's slides, A17 commented during the focus group: *"Now I'm curious what everyone else had, because I wanna figure out, like, what could be better, because clearly I didn't figure it out."* With a suite of options to try, especially if the system made recommendations, A17 might have been able to test different things to better understand the properties of his ideal slide deck.

While people appreciated the concept of a tool that made slides more accessible for them, the presentation session revealed some issues: namely, it increased the complexity and mental load of attending a presentation. Some participants found it fairly easy to follow along with their own copy of the slides as the presenter spoke, but others like A15 and A16 found themselves occasionally getting lost or paying less attention to the content because of the overhead. Specifically, people were concerned about being able to stay synchronized with the presenter's location in the slides. A14 explained that, ideally, they would like to be able to full-screen their own custom slides and have a small overlay in the corner showing the presenter's slides for synchronization purposes. A6 felt similarly, and they suggested having a feature that allows them to jump to the presenter's location in the deck, thereby re-synchronizing their slides with the presenter's. On the other hand, almost everyone who requested a deck to use before or after the presentation appreciated the changes. However, they consistently wanted more context for each slide, which could be provided with a transcript or a summarized version of the transcript in the speaker notes of each slide. These results indicate that custom slides can be useful, but a tool would need to work to combat the increased overhead of synchronizing slides during a presentation.

Finally, participants noticed edge cases where our implementation of their requested changes was insufficient. For example, images embedded in slides conflicted with participant changes around font and coloring, as we could change the contrast ratio of all slide text, but could not change the contrast ratio of words in images. Participants were also adamant about the need to maintain font hierarchies, meaning that the ratio between the title font size and the body text font size stayed relatively consistent.

6.4.5 Presenter Perspectives

We concluded our research with interviews with four slide deck presenters to understand their perspectives on the automatic changes a system would make to their slides. Presenters were overall in favor of the motivation for the system: they recognized that meeting individual audience members' needs all at once was infeasible with a single deck, and they were optimistic about the idea of technology helping customize the decks. Presenter participants appreciated that the system could help them ensure that their presentations were more accessible, especially if they didn't have sufficient existing accessibility knowledge. P3, who was familiar with basic accessibility best practices, appreciated the safety net the tool provided him *"The pressure to like, be perfect ... is a little bit* *reduced,"* though he confirmed that this tool would not *replace* his accessibility efforts, since he recognizes that algorithmic systems do not always perform with high enough accuracy. P4, an accessibility expert, was optimistic about the system, though they noted that it would need to work with existing assistive technology to avoid becoming an Accessibility Overlay[5] [The A11Y Project Team, 2021, Feathers, 2021].

In response to the changes that we made to their slides, the participants were largely amenable to changes to the slide color and fonts, but they were unhappy or skeptical if the tool summarized their content or made major layout changes. Additionally, they found cases when it could be useful for themselves while authoring slide decks.

Participants generally felt positively or neutrally about font or color changes

All participants were fine with the color changes that we applied to their slides, with some participants preferring the dark-mode versions of slides that we made over their original slides. P1 appreciated when, in changing her slide colors, we maintained some of her accent colors to maintain a similar "vibe" to the original presentation. Similar to audience member participants, presenter participants did find edge cases where a naive implementation of the change was not acceptable. P1 was not pleased when the color change that we applied to her slides changed both black and blue text to be white, since the blue text was specifically used to highlight a different type of data. P4 pointed out that changing colors could also be unfavorable if the presentation was about color theory or used specific brand colors for a client. Finally, P2 was overall fine with the changes being made by the hypothetical system, but did feel like the consumer was *"losing the fact that, like, I made my slides pretty."* Other participants commented that well-designed, aesthetic slides could add to the consistency or professionalism of the slides, and losing proof of these efforts could have a negative impact on presenters.

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[5] Accessibility Overlays are critiqued for being limited in scope while not fixing any of the underlying accessibility issues. Additionally, some argue that they allow web creators to shirk their responsibility to learn about and operate accessibly [The A11Y Project Team, 2021, Feathers, 2021].

Participants were skeptical about or disliked changes to layout and text summarization

Layouts: Participants were fine with most layout changes, if they felt the layout changes were executed well. For example, all presenters experienced at least one of their slides getting split into two because of an increase in font size. Presenters emphasized that slides must be clearly labeled as being split up, though P4 noted that it might still be tricky for audience members to understand when to change slides. They also emphasized that the split point needs to be at the "right" place in the content: for example, P2 had a 2x2 table that was ok to split by column, but not by row. She was not confident that an automated tool could correctly distinguish between different ways of splitting the content. P1 was similarly nervous that the tool would not recognize and maintain some of the key spatial relationships that she built into her decks.

Summarization: Participants were even more skeptical about the tool performing accurate summarization of their content. They were especially concerned about summarization algorithms misrepresenting what they intended to say: *"if the summarization ended up saying something that is not what I intended or agreed with … and then I got quoted out of context or like misunderstood, that would be a problem"* (P3). P2 felt similarly and consequently wanted to double check every summarization that the tool produced, which would significantly change the requirements of the system. Together, these results indicate that while most changes to font and colors would be welcome by presenters, users would need significant trust in the capabilities of an AI to let it handle layout alterations or text summarization.

Tool use by presenters

While we imagined a slide customization tool to be used by audience members in presentations, the presenters also wanted to use the tool in different scenarios. P2 noted that she wanted to use the plug-in for her own needs when she was developing slide decks, for example, turning slides to dark mode when she's editing at night. Multiple participants wanted to receive suggestions for how to make their decks more accessible when selecting or building a template; they were much less enthusiastic about the tool making changes after they built content, and P3 in particular was staunchly opposed to the tool making changes to the slides he was going to present without informing him. P4 liked the idea of being able to preview the types of changes audience members could request: for example, if people could enlarge fonts and images, she would want to see what that layout would look like and see if she needed to upload a higher resolution image or rearrange the content to better fit. Overall, presenters were happy to get suggestions for general accessibility best practices for slides if they could still have agency in their design process.

6.5 Study Discussion

In this work, we conducted focus groups with people with a diverse range of access needs. We enumerated what issues they had with slide decks, and relatedly, what properties of slide decks must be customizable to allow for accessible consumption of slide decks. Moreover, beyond echoing the calls for more customizable interfaces [Gajos and Weld, 2004], we performed a technology probe that helped us understand the specific contextual factors in a presentation environment that will be impacted, should such customization technology be developed and deployed. Finally, we engaged another critical stakeholder, slide deck authors and presenters, to understand their priorities and concerns with such a tool. In this section, we synthesize the learnings from these multiple stakeholders across all three phases of this study and present design recommendations and specifications for future accessible slide deck technologies.

6.5.1 Bespoke, Fluctuating Access Needs

Participants' experiences demonstrate that **slide related access needs are bespoke and fluctuate.** Mack and McDonnell et al. emphasize that HCI accessibility research needs to see chronically ill people as having fluctuating access needs that can be addressed with accessibility technologies [Mack et al., 2022b]. Our studies demonstrate several examples of people with chronic illnesses having needs that fluctuate throughout the day, which our slide plug-in could successfully account for. Furthermore, many individuals in our sample had conflicting access needs that were specific to their abilities, such as some people preferring dark background slides and others wanting bright colors [Hofmann et al., 2020, Mack et al., 2021b]. But some participants' access needs fluctuated further, causing them to need different levels of contrast based on the room they're in, the device they are using, or the fatigue level of their eyes. Thus, it is infeasible for slide deck authors to create decks that meet all audience access needs at all times with a single deck.

Therefore, we described the concept a system that allows audience members to customize their own local copy of the slides to meet their access needs in-the-moment to our participants, which was generally appreciated. However, we want to emphasize that **such a tool does not absolve presenters from thinking about accessibility in their design process**; there are still accessibility best practices that are worth considering in all slide decks because they improve slide usability for the majority of people in many scenarios (e.g., ensuring font is at least size 18pt). At the same time, our tool supports people who are outside of this majority who have more specific needs.

6.5.2 Power and Autonomy in Slide Contexts

Participants' experiences highlight that **power dynamics are a key factor in determining how accessible a presentation is for audience members**. Participants described instances where people in power were not dedicated to accessibility, like not wanting to slow down a presentation when an executive is present in a meeting. These scenarios led to participants feeling uncomfortable or bothersome for asking for access changes.

Moreover, we found that **giving audience members a copy of slides increases their autonomy and ability to meet their own access needs in a presentation session.** Indeed, having their own bespoke copy of the slides gives the users more control over both how slides look and the pace at which they progress through slides, which are both lacking in today's slide consumption paradigm. Participants offered experiences that demonstrate "crip time," or people with disabilities (or related identities) having different experiences in both passing of and experience with time [Kafer, 2013, Samuels, 2017]. Having their own slides allowed participants to consume the slide content at a pace that felt useful for them, be that faster or slower. In summary, while having a personal copy of the slides does not fix all accessibility issues, it is critical for accessibility and increasing audience member autonomy. We echo the calls from existing organizations to presenters to share copies of their slides before presentations [University of Colorado Boulder Digital Accessibility Office, 2024].

6.6 System Results

Our initial interview results with audience members demonstrate that one slide deck does not fit all; access conflicts required different people to each have individualized decks. Moreover, some individuals described having fluctuating access needs, which led to different slide preferences at different times. However, we recognize that in most presentation settings, the presenter does not have the accessibility expertise nor the time to make multiple, bespoke decks for each audience member with access needs. Therefore, we identified that a technological solution is apt for contexts where capacity is limited, access needs differ between people, and access needs change in the moment.

In this section, we first describe the requirements for the ideal functionality of such a tool, based on the features described by participants. We then describe our implementation of a Google Slides plug-in and API limitations that prevented us from developing all of the user-requested features. Therefore, we conclude by discussing the importance of robust APIs to support accessible technology ecosystems, and we outline requirements for what a slide deck API would have to expose to fully support the ideal system we designed.

6.6.1 Design Features and Goals

Our audience member and presenter participants described several properties and broad features that a tool that makes customized, accessible slides should have. Audience member participants made clear that they need to be able to **run the tool themselves**. Partially, they wanted to be able to try out different styles and see what works best, but also, they commented that they might not be sure of what features they need in a certain context before they arrive. Relatedly, these usage scenarios imply that the tool must be **quick to run**. The tool should not take five minutes to apply changes to a deck; it should be highly interactive. The variety of needs that a single participant could have indicate that the tool should have some **memory or profiles** so that users do not need to keep re-inputting their access needs every time they change. Finally, from the design probe activity, participants indicated that the cognitive load of following along with a personalized copy of slides could be lessened if the tool allowed them to see the presenter's original slides and **synchronize their location** in their copy of the deck with the presenter's location.

From the presenter interviews, we discovered it was important to presenters that the changes that audience member's were making to their own personal copies of slide decks **did not impact the presenter's original copy of the slides**. Further, some presenters wanted the ability to **preview changes** the tool would make to audience members' slides so that they could make adjustments if needed (e.g., editing aspects of the redesigned slide layouts). Other presenter participants wanted the ability to **apply the tool to their own slides** to better meet their own preferences while authoring slides (e.g., authoring in dark mode at night) or to edit their own deck to be more accessible for more individuals in their audience on average.

An ideal tool to create customized accessible slides would support the following features, derived from participant preferences:

- **Ability to change font properties.** This tool should allow the user to specify the font size, font family, and font color. This feature will ideally maintain font hierarchies, meaning, if the smallest font in the presentation is increased from size 15pt to 20pt, then the other fonts in the deck will increase proportionally. Moreover, when font increases such that elements overlap or overflow off the slide, content should be split into two slides. The division between the two slides should be at a logical point in the flow of the content, and the resulting slides to remain useable (e.g., content order be maintained, still look visually appealing). It should also be clear to the user if a slide was broken in two (e.g., titling the slides "[TITLE] (1 of 2)" and "[TITLE] (2 of 2)")

- **Ability to change colors.** Beyond changing font color, the tool should allow the user to change slide background colors. More specifically, users would benefit from the ability to set the minimum or maximum color contrast throughout the document so that it can be lower or higher on-demand. Changing colors kept some study participants engaged, and therefore having a random feature for font color (and font family) could be useful to some system users. These features would ideally apply to both text embedded in the slides *and* to images used with the slides.

- **Ability to alter images.** A slide customization tool must also allow the user to resize, add, and remove images. To satisfy presenters' requirements, images must maintain high image quality when resized. The system should also detect if images are relevant or not and be able to remove irrelevant images to serve audience members who report being distracted by images. Yet, the tool should also be able to insert more images related to the topic at hand to serve visual learners. Finally, all images should have complete, concise alt text.

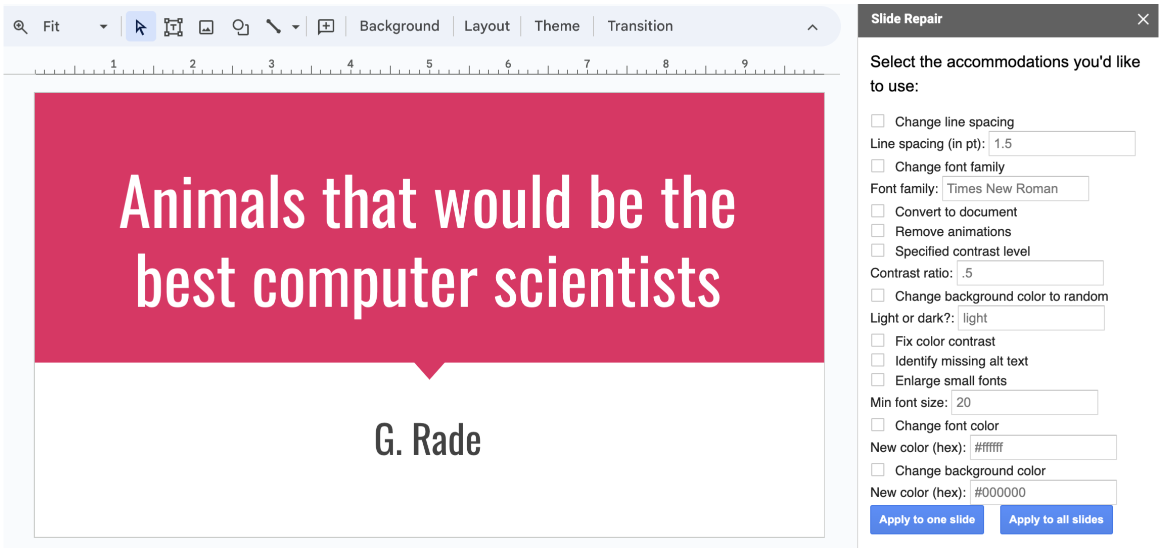
- **Ensuring nonvisual access.** This system should also maintain and improve nonvisual access for people who use screen readers or are BVI. All slides should have slide numbers and content should have a logical tab order within the slide deck. Tab order should be robust (i.e., remain correct even if an author uses an unusual slide design, like putting a title at the bottom of the slide rather than the top). Finally, an ideal tool should be able to export the document into an easier-to-consume format, like a text document or HTML.

- **Improving content understandability.** Visual spacing is a key aspect of content understandability in slide decks, and an accessibility customization tool should allow the user to control this aspect of slides. The tool should have the ability to change the line spacing across slides, and more specifically the spacing between bullet points. The tool should also allow users to have more white space, or less text, per slide. Participants differed in whether they wanted to accomplish having less text per slide by breaking a slide up into multiple slides with less content each, or summarizing the text on a slide (oftentimes determined by how important they felt the text content was), and therefore this system should be able to support both approaches.

- **Other.** Finally, this system should be able to remove animations from slides and provide content warnings if the deck has triggering content.

6.6.2 System Implementation

We chose to build our tool on top of the Google Slides public API. The tool is written in JavaScript and is hosted through Google App Scripts, allowing it to interact with Google Slides presentations in the user's Google Drive account. The interface for the tool presents users with a checklist of all possible features, and it allows the user to apply them to one or all slides (see Figure 6.3). We were able to support the following functionality through the existing features in Google Slide's API, which we group according to the different feature categories outlined above:



Animals that would be the best computer scientists

G. Rade

Select the accommodations you'd like to use:

☐ Change line spacing
Line spacing (in pt): 1.5
☐ Change font family
Font family: Times New Roman
☐ Convert to document
☐ Remove animations
☐ Specified contrast level
Contrast ratio: .5
☐ Change background color to random
Light or dark?: light
☐ Fix color contrast
☐ Identify missing alt text
☐ Enlarge small fonts
Min font size: 20
☐ Change font color
New color (hex): #ffffff
☐ Change background color
New color (hex): #000000

Figure 6.3: A screenshot of our system implemented as a Google Slides plug-in. This menu allows the user to select what accessibility changes to apply to the slides.

- **Font size and family:** Our tool allows the user to select the font family and the minimum font size that they would like to be used across one or all slides.
- **Colors changes:** Our tool allows the user to input the color of the slide background that they would like to use across one or all slides. Further, when changing colors to meet a specific contrast ratio, our tool maintains the author's hue, but adjusts the saturation until the proper color contrast is met. The user can also specify the level of contrast that they would like throughout the document, so that it can be higher or lower on-demand. Finally,we offer two "random slide color" options, one for lighter colors and one for darker colors, where the tool randomly makes the slides different light or dark colors.
- **Image changes:** Our tool helps authors identify which images are missing alt text by marking them with a red rectangle overlay, thus allowing slide deck authors to identify which images still require alt text with a quick glance.
- **Content understandability:** Our tool allows the user to set the line spacing across one or all slides.

- **Nonvisual access:** Our tool supports the ability to export a slide deck into a Google Document that includes slide numbers and headings to allow for easy screen reader navigation.

6.6.3 API Limitations

While we were able to implement many of the key features for an ideal slide accessibility customization system identified in subsection 6.6.1, we could not achieve all features or the robustness of features participants desired due to limitations with the Google Slides API. We had in fact tried to implement this plug-in in both Google Slides **and** in Microsoft PowerPoint; both had their limitations. This is a significant obstacle to allowing external developers to participate in making commercial tools accessible.

The largest obstacle with both APIs was that it was inefficient or impossible to get a tight bounding box for textual content in slides. While both APIs exposed the size of the text box that contains the text, they do not readily surface whether or not the text takes up a portion or all of that text box. Having a tight bounding box on how much space text occupies is critical when determining whether different elements can fit on a single slide. Thus, changes that required splitting one slide into two and/or rearranging the layout of a slide were not possible to implement robustly with the current APIs. However, if the API exposed a tight bounding box for text, researchers could leverage existing document optimization layout techniques to create logical layouts for slide decks [Jacobs et al., 2003, Yang et al., 2016, Piccoli et al., 2012].

Further, while Google Slides and Microsoft PowerPoint support making external API calls, these calls can slow down the runtime of the plug-in considerably, and in the case of Google Slides, plug-ins are limited in the amount of time they can run. Integration with external APIs is critical for some ideal features, such as generating new images to support content, identifying the main content of images or text, summarizing text, or changing the color properties of PNG or JPG images. Thus, while there are promising methods to implement some features desired by users, both their current runtime and API timeout properties mean their implementation could result in compromising on the design principle of interactivity.

Finally both softwares' APIs are missing key functionality to support all features. For example, in PowerPoint it is not possible to insert an image or access its alt text, and in Google Slides it is not possible to access animations via plug-ins. Consequently, we outlined what features of APIs are required to build a robust system that meets the participants' desired customization abilities (Table 6.4).

Table 6.4: Through building our prototype, we enumerated the capacities that a slide tool API must support to allow a plug-in to meet the access requests of the participants

User-facing Feature	**API Requirement**
Ability to change font properties: font size, font family	Access and set font size
	Access and set font family
	Access a tight bounding box measuring the space text occupies
Ability to change color properties: slide and font colors, contrast levels, color palettes	Access and set font color
	Access and set slide color
Ability to interact with images: enlarge images, add additional images, remove decorative images, access images with screen readers	Access and set alt text
	Access and set image size
	Insert and delete images in slides
Content understandability: reduce text on a slide, break text up into multiple slides, add context in speaker notes, increase line spacing	Insert and delete new slides
	Insert and delete text in slides
	Access and set line spacing
	Access and set speaker notes
	Access a tight bounding box measuring the space text occupies
	Ability to work with other API's
Ensuring nonvisual access: page numbers, tab order, ability to export content into another format	Access and set page numbers
	Access and set tab order
	Ability to write to another file
Other: ability to remove animations	Access and set animations

6.7 System Discussion

6.7.1 A Call for More Robust APIs

Experts underscore how integral robust APIs are to the accessibility ecosystem. One of the key ways disabled people (especially people who use screen readers) interact with technologies is through open source plug-ins or services built on top of the APIs of popular software. Our proof-of-concept system demonstrates some of the shortcomings in existing APIs. Some critical features that are available and used in the graphical user interface are missing corresponding API calls. These omissions prevent third-party developers and researchers to build robust tools that meet disabled users' desired functionality. We echo Miele's call for commercial tools to expose as much of their public interface functionalities as possible through APIs to allow for the development of third-party plug-ins for accessibility [Miele, 2024].

6.7.2 Implementations with Generative AI

As this work was conducted in 2024, during the height of the generative artificial intelligence (GAI) boom, we considered utilizing GAI tools to perform some of the changes to slide decks that participants suggested. We performed an informal investigation the features and performance of a variety of tools: 1) Gemini's integration with Google Slides, 2) ChatGPT, and 3) a "SlidsGPT," a custom service built on top of Chat GPT. We also attempted to test PowerPoint's "ChatGPT for PowerPoint" tool, however, we could not get the plugin to install successfully.

We found that these available, state-of-the-art GAI tools could accomplish a few tasks that participants requested, but could not accomplish the vast majority. With respect to the successes, Gemini's integration with Google Slides could successfully summarize a slide with often reasonable accuracy, which participants indicated could be useful for text-dense slides. Multiple generative AI platforms can summarize image contents, which could be helpful to slide authors in crafting alt text.

In the context of this study, we mainly focused on the use case of how to remediate an existing inaccessible slide deck, rather than accessibly creating a new slide deck from scratch. Consequently, the main limitations that we encountered with these GAI tools were that 1) very few tools accepted a slide deck as input, and 2) the tools that did accept a slide deck as input focused on generating new content in the deck rather than altering existing content. For example, while Gemini could operate on an existing slide deck, it could not change any existing slides' font color or size successfully; nor could Gemini generate a slide with these properties specified. Similarly, SlideGPT could create a brand new deck of slides, but could not alter an existing slide deck. Even when creating a brand new slide deck, we could not successfully generate slides with specific accessibility guidelines, like a deck having a black background with white text.

Because of these limitations, we turned to utilizing the API of an existing, popular tool, since prior HCI accessibility work has demonstrated that systems are limited in their utility to the disability community if they are not built on mainstream platforms [Zhang and Wobbrock, 2022].

6.7.3 Limitations

First, this study was conducted in a US-based context, and other geographic locations have different relationships with slide deck use and accessibility considerations. Furthermore, it was oftentimes difficult to understand if a participant was describing a feature that made a deck more accessible for them because of a disability, or just a feature that would make slides generally easier to consume. However, our results indicated that for many people (people who were neurodivergent, people using screen readers) reducing the cognitive overhead for a talk would increase accessibility. Thus, we consider all of the features the participants shared as relevant since easier-to-understand decks are more accessible decks. Finally, we emphasize that the results from the presenter participants are only a preview of the types of considerations that might come up from other stakeholders of a slide deck accessibility plug-in because of the small sample size. To fully understand this stakeholder's needs, more extensive research should be conducted.

With respect to our methods, with qualitative methods like focus groups and interviews, it is challenging to get as much of a breadth of experiences as one can find with something like a survey tool. However, we sought to understand not just what made slides accessible for participants, but why those features were helpful and how they changed across contexts. These details, we decided, would be more easily gained via an interview-based method. For the second phase of the study that used a technology probe, there was likely a pressure for participants to pay more attention and think more highly of the slides because they were in a study where they were clear on the motivations of the study after their participation in phase one. The researchers conducting the sessions actively encouraged participants to critique the tool, and they did voice some negative aspects of the experience. However, we encourage future research to consider doing a longer term field deployment of the tool to get a more ecologically valid evaluation before performing any wider deployments of such a tool. At the same time, doing a virtual "labratory" based study allowed us to probe in depth about specific interactions immediately after they occurred.

6.8 Conclusion

People have diverse access needs relating to slides, and these access needs fluctuate frequently. Technology that addresses access for multiple audience members should consider how to provide solutions that allow for customization at the individual level and are interactive and easy to use. We conducted focus groups and interviews about slide deck accessibility with 17 audience members who have access needs, performed a technology probe to understand tool constraints with 14 of these participants, and interviewed 4 authors and presenters of slides to understand another stakeholder's perspective. We used their insights to inform the design of a slide show software plug-in that allows users to customize slides to automatically meet their own access needs. Finally, we implemented a subset of features requested by the participants as a Google Slides plug-in. In summary, we emphasize that slide deck access needs are bespoke and fluctuate, and that technology needs to be designed with this truth in mind.

Chapter 7

DISCUSSION, FUTURE WORK, CONCLUSION

7.1 Discussion

In this thesis, I demonstrate that access provisioning in a group context depends on a multitude of factors, many of which fluctuate on the scale of years, days, or even minutes. Studying chronic illness (chapter 3) makes visible the ways that access needs can vary drastically within an isolated individual across short time spans. My work with mixed ability teams (chapter 4, chapter 5) reveals additional layers of complexity that are introduced in context with multiple disabled people who possess varied roles and power within a group. Combined, the results from these three studies identify key factors of group interactions that fluctuate and impact access provisioning. My final study demonstrates how to design a system to meet fluctuating access needs, based on the knowledge gained from my qualitative studies. I then validate such a tool's efficacy with people with access needs via a design probe (chapter 6).

7.1.1 Fluctuating factors that impact group access provisioning

In chapter 4, I established that a mindset of "anticipation and adjustment" benefits planning accessible research. Expert research and community organizer participants demonstrated the considerable thought and care that went into planning their studies and events. They repeatedly emphasized the importance of "doing your homework." Inevitably, no matter how much they planned, circumstances changed, and they often needed to be ready to adapt their protocols. Though, the more prepared and knowledgeable a facilitator was, the more capacity they often had to customize their surroundings to meet fluctuating needs.

While the study outlined in chapter 4 mainly focused on access in the context of research, I believe that this framework is applicable more broadly. For example, several of the participants in chapter 4 were hosting community events and described an "anticipate and adjust" mindset. This motif further appears in my other studies. In chapter 3 and chapter 5 I identified different factors that can fluctuate and then require people to adjust how they provide accommodations. For example, in chapter 3, the chronically ill authors describe preparing to go to work by bringing a multitude of things that they might need if their symptoms were to get bad. Then, if something does go awry during their days, they have all the tools that they could need to adjust their day to recover from the spike in symptoms.

A key contribution of my dissertation is improving readers' ability to "anticipate" how factors that impact access provisioning can change and thereby better prepare them to to "adjust" to meet access needs in-the-moment. I compile the factors described across the past four chapters and present them, along with examples of how they can fluctuate, in Table 7.1.

Table 7.1: Different factors that impact access provisioning and how they might fluctuate.

Factor	Fluctuations
Individual abilities	• New disability might onset • Abilities might change over years • Abilities or symptoms might change throughout the day
Different people's abilities	Different people (even with same formal disability or condition) might have different expressions of abilities or symptoms
Spatial context	• Virtual environment • Physical environment
Social context	• Access synergies • Access conflicts • Power dynamics • Accessibility competency of group members
Capacity	People might have more or less capacity to perform access labor, recognizing that disabled people might be receiving and providing access
Visibility of disability	The visibility, or desired visibility, of a disability to others might shape when and how someone asks for access needs to be met and their preferred accommodations

It is important to note that these factors are not fully independent nor isolable; often, several are changing at the same time. Consider the example introduced in chapter 1, where El, Yuxuan, and James are working in a group. El is hard of hearing and Yuxuan has a chronic illness. If Yuxuan starts getting a migraine from her chronic illness, that might change the space the group wants to meet in (somewhere quiet or dark), the visibility of her disability (she might start wearing dark sunglasses), or the capacity that she have to meet other group members' access needs (checking the accuracy of the captions El uses). Moreover, in groups, I have also demonstrated that accommodating the group is not always as simple as combining the accommodations that two people receive independently. For example, we saw in chapter 5 that access conflicts might prevent a group from simply doing the typical accommodations for someone who is blind and for someone who is Deaf when they are both participating in an activity.

Finally, it is important to note that both technical and nontechnical solutions exist to provision access when these factors change. For example, consider El, who is hard of hearing who primarily lip reads, but has less capacity to lip read when the lighting is bad. If the lighting in a group meeting becomes worse (e.g., the sun sets while meeting outside), there are multiple ways to provide access. A nontechnical solution to provide access might be asking people to move to a place with better light. Whereas, a technical solution might be to pull out a phone and use automatic speech recognition.

7.1.2 Fluctuation as a guiding principle for technology design

Finally, I demonstrate how the factors in Table 7.1 can guided system design by using the system from chapter 6 as an example.

In chapter 6, we examined the context of meeting diverse access needs for multiple people during slide deck presentations. While considering different design options, we considered the factors in Table 7.1 to guide our process. In order to support multiple different users at once (**different people's abilities**), we recognized that people using our tool would need to be able to input their own needs without it impacting the experience for other audience members. However, we also wanted the solution to avoid a burdensome setup process that would discouraged a user from further customizing the slides if their own needs changed overtime. For example, we wanted to support a single audience member in changing the font colors and contrast based on their eye fatigue on a particular day (**individual abilities**) or depending on the lighting of their space (**spatial context**).

Finally, we sought to make our solution easy to turn off or on based on who else was present (**social context**), allowing people to prevent disclosing their disability to other people unnecessarily (**visibility of disability**).

The design that we arrived at to meet these design constraints was a plug-in built into a common slide deck authoring platform like Google Slides or PowerPoint. If audience members received their own copy of the slide deck[1], they could open it in one of these tools and select the accessibility options that work best for them with the plug-in. The plug-in would then make the requested changes to the user's local version of the slides (e.g., increasing the font size) without changing the experience for other people in the audience. The plug-in can be easily turned on or off at the user's request. The plug-in could also have stored profiles, allowing users to switch between different preferences easily based on their needs in-the-moment.

Thus, with this example, we designed a system that accounts for the different fluctuating factors from Table 7.1.

7.2 Future Work

This dissertation uncovers avenues for future research, including 1) investigating other areas where bespoke accessibility would be helpful, 2) studying how technology can best serve people with chronic illnesses or others' whose individual access needs fluctuate often, and 3) examining what other factors are important for facilitating group access.

7.2.1 Additional contexts for bespoke technological tools

In chapter 6, I studied how slide decks could change to meet the needs of diverse audience members with little effort from audience members or presenters. Slide decks are just one example of *shared materials* (see chapter 4) that could be customized to meet bespoke user needs. Future research can investigate other domains to apply bespoke change to, including interfaces, images, and websites.

Furthermore, the other dimensions that we enumerate in chapter 4 are areas to consider how technology can meet fluctuating access needs: space, time, and communication. Regarding space, future research can investigate if there are ways for technology to aid in adapting spaces to bet-

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[1] Many of our participants did, and it is regarded as an accessibility best practice.

ter meet the needs of its occupants (especially virtual spaces). Regarding time, there are many disabilities and related conditions that cause people to operate on nontraditional timelines or at non-traditional hours. Remote work technologies have already been a boon to many disabled people who are more able to work on non-traditional hours [Tang, 2021], and future work could consider how technology might work as a time-saving tool for people whose disabilities make day-to-day tasks take longer to complete. Finally, regrading communication, technology mediates many different forms of communication today. Therefore, technology is aptly suited to remind or enforce accessibility norms, which could be updated based on who is communicating and what each person needs at that moment. Consider a social media group that verifies that all posts meet accessibility guidelines for the group, given its current membership.

7.2.2 Automatic interface adjustment for fluctuating access needs for chronically ill people and beyond

In chapter 3, I present a framework for how to engage in research with chronically ill individuals, since they have not traditionally been considered in accessibility research [Mack et al., 2021c]. A worthwhile next step for the HCI accessibility research community is to start engaging with chronically ill communities to address their accessibility needs. Codesign efforts that investigate how technology can adapt interfaces to best meet chronically ill users' needs in-the-moment would be useful. For example, mobile apps could have versions of interfaces that increase click target sizes when the user has limited dexterity; route planning apps could adjust based on detected differences in the gait of the user or the mobility aids they use; and search results can include more or less detail based on brain fog or attention levels.

One interesting avenue for investigation is how to best adapt to users' needs without causing undo burden to the user. Having to program the exact interface settings (e.g., dark mode, larger click targets, larger font) every time the user opens an app involves considerable effort. Technology, especially with recent AI advancements, provides an interesting opportunity to automatically adjust interfaces based on data streams like smartphone sensors or interface interaction traces. Such sensing could automatically cause adjustments to interfaces and interactions without burdening the user to input their current state. However, these methods also raise questions around 1) privacy, and 2) whether embodied elements of chronic illness can be sensed accurately by external tools.

Furthermore, while chapter 3 argues that access needs and preferences can change drastically for people with chronic illnesses, I posit that this framing is a useful lens to apply to other kinds of disabilities as well. For example, some mental health conditions are cyclic in nature (e.g., depression) and people might prefer their technology support them differently when they are in or out of a depressive episode. Similarly, people who are neurodivergent can have days where they hyperfocus and days where they struggle to focus on a task, motivating the need for different supports on different days. Even disabilities that have been heavily studied in accessibility literature might find benefit from adopting this lens. For example, some people with visual disabilities in our study found that they need more support to engage with screens as the day went on and their eyes fatigued chapter 6.

7.2.3 Continuing to promote accessible group interactions with and without technology

My work focused primarily on group contexts where there was buy-in from stakeholders to produce an accessible experience; the group members in chapter 4 and chapter 5 were all committed to providing access for all members. However, convincing each person in a group to prioritize and value accessibility is nontrivial. Future research must examine strategies for showing group members the value in making group interactions an inclusive experience. Workplaces are often environments where group interactions are abundant. Future research can investigate if there are ways that technology can educate teams on why accessibility is important in workplace settings, in hopes of increasing teams' desire to create accessibility norms and best practices.

Finally, further research in automating access provisioning with technology will necessitate an investigation into which aspects of access provisioning should be handled by technology and which should not. As Mingus describes in her writings, meeting each others' access needs can be an intimate experience [Mingus, 2011]. There are certain times and types of interactions that people with access needs will *not* want to be replaced with technology. We must build technology with the understanding that it is not always going to be people's preferred solution.

7.3 Concluding Remarks

I am excited that there is enough accessibility research in this world such that I can write a dissertation about how to make our views of group accessibility *more nuanced,* rather than initially defining them. Pulling from Dolmage's critiques of universal design implementations, this dissertation argues for access provisioning to be a continuous conversation rather than a static set of checklist items to be completed before a group meets. As Dolmage writes about creating inclusive learning environments: "we are all involved in the continued production of space," I argue that all people in a group are involved in the *continued production of access*[Dolmage, 2015].

In the preceding chapters, I identify and describe core factors that can fluctuate and impact how access is provisioned in group contexts. My hope is that, in considering these factors, we can view accessibility in a way that more closely mirrors the lived experiences of disable people day-to-day, glimpses of which we can see in the writings of disability activists and community members [Mingus, 2017, Piepzna-Samarasinha, 2018, Wong, 2022, Invalid, 2019, Piepzna-Samarasinha, 2022]. I encourage the field of accessibility research to continue striving towards the goal of creating more nuanced frameworks, paradigms, and technologies that encourage accessible interactions, as defined by disability communities.

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