

Anticipate and Adjust: Cultivating Access in Human-Centered Methods

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ABSTRACT

Methods are fundamental to doing research and can directly impact who is included in scientific advances. Given accessibility research's increasing popularity and pervasive barriers to conducting and participating in research experienced by people with disabilities, it is critical to ask how methods are made accessible. Yet papers rarely describe their methods in detail. This paper reports on 17 interviews with accessibility experts about how they include both facilitators and participants with disabilities in popular user research methods. Our findings offer strategies for anticipating access needs while remaining flexible and responsive to unexpected access barriers. We emphasize the importance of considering accessibility at all stages of the research process, and contextualize access work in recent disability and accessibility literature. We explore how technology or processes could reflect a norm of accessibility. Finally, we discuss how various needs intersect and conflict and offer a practical structure for planning accessible research.

CCS CONCEPTS

• **Human-centered computing**; • **Accessibility**; • **Accessibility design and evaluation methods**; • **Human computer interaction (HCI)**; • **HCI design and evaluation methods**;

KEYWORDS

accessibility, Human-Centered methods, disability, user research



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1 INTRODUCTION

Methods are inseparable from how we study people and the technology that enables them. They include the strategies and approaches we take to answer research questions and share new information with our research communities. These “ways of knowing”, have wide-ranging impacts, “from how we frame a problem, to what we think about, how we think about it, and what we do” [49]. For example, semi-structured interviews reveal insights into people's specific experiences, whereas usability tests generate knowledge around prototypes. As HCI has evolved as a discipline, methods have widened to embrace a spectrum of approaches, from ethnographies to experiments. These methods are underpinned by a range of epistemic commitments, from amplifying people's unique lived experiences to controlling variables. In concert, accessibility research has grown to become among the most popular research areas in HCI [43], which continues to expand its methodological approaches, such as a recent embrace of autoethnography, to enrich understandings of people with disabilities¹ [30, 63]. Further, the representation of disabled CHI authors is increasing, as is an awareness of the need to make HCI professional contexts more accessible [71].

However, HCI risks excluding and harming people if methods and studies are crafted without centering the needs of minoritized

¹We use both person and identity first disability language, reflecting that our participants used a mix of both. See [57] for more details.

groups. For example, scholars have critiqued binary gender encodings in surveys [9, 15, 62], white and wealth supremacy embedded in participatory design [25], and the erasure of disabled voices in HCI research [70]. 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 [2, 20, 28, 70]. 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 [18, 31, 55, 56, 70], 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 paper, 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 [18, 29]. All interviewees worked to make activities which are associated with HCI methods accessible, such as workshops, interviews, and usability studies [72]. 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 surface 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 offer strategies for planning accessible research studies.

2 RELATED WORK

HCI has embraced a variety of methods [40, 49], and literature reviews have enumerated their use [73]. For example, recent studies recruiting people with disabilities commonly leveraged interviews, usability tests, and controlled experiments [43]. But for a few exceptions (e.g., [40]), 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.

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 [40] and a report published by the Nielsen Norman group [12]. 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 [12]. Turning to research, a few works focus on accessibility considerations in working with people with a specific set of abilities [14, 53, 61]. 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., [37, 50]). 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.

2.1.1 Adapting Methods to Increase Accessibility. Scholars have made several communication adjustments to make their studies more accessible [14,21–23,33,35,37,53,65,67]. For example, some work encouraged researchers to consider how people may contribute in nondominant ways (e.g. nonspeech options during real-time interactions [23, 37]). Additionally, researchers have offered multi-modal communication by, for example, supplementing real-time instructions with visual aids [23, 33, 37, 67]. 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 [53], and Johansson et al. scheduled discussions to occur over several sessions while working with participants with mental health and cognitive disabilities [33]. 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 [16].

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 [41], CAD [26, 59]), they turned to physical, lightweight prototyping mediums, like using wood and fabric to design circuits [32] or other materials such as foam, Legos, Play Dough, and Wiki Stix for general design tasks [32, 50]. Other times, visual-dominant, paper-based prototyping activities (e.g., brainstorming) were eschewed for more multimodal, rich methods of engagement (e.g., bodystorming) [44, 45]. 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.

2.1.2 Negotiating Power and Access Needs During Studies. Access arises (or is hindered) through interactions between those who design, run, and participate in studies. Each stakeholder enters a study with their own identity and perspectives [7, 38, 60, 67], and the overarching study is not independent of broader systems of power or oppression which further shape identities and interactions [7]. For example, during an autoethnography, Yıldız et al. questioned when and how to disclose the researcher’s disability, and if disclosure occurred, they considered how the researcher’s identity affected their participants responses around access and disability [69]. Notably, there exists a power difference between a researcher and participant. Spiel et al. note that participants’ power to define research directions and contribute to the work further diminishes when disability overlaps with other identities like being a child [61]. Other prior studies described explicit measures to counteract this power dynamic; for example, Johansson et al. held study circles to facilitate democratic session topic selection, and Williams and Gilbert recommended building in explicit points for checking in about study pace and reconsenting [33, 67].

Additionally, some researchers have disability identities and/or access needs that must be considered in planning and performing methods, which are similarly influenced by power dynamics. Prior work has focused on intersections of access needs on professional teams. Hofmann et al. found that “access conflicts” occurred when accommodations for one team member hindered access for another, but also highlighted that sometimes access needs synergized in ways that made for creative, collaborative work [27]. Consider Jain et al., where all authors had different disabilities and drew on each of their strengths to reduce others’ access barriers while writing their publication [31]. Similarly, Chua [10], who uses captions, utilized the access provision to do in-the-moment member-checking; participants could read the transcript soon after it was generated and adapt their response as needed. Finally, Mack et al. found that power dynamics influenced the accessibility of a research team, concluding that those in power leading by example with accessible practices was crucial in establishing accessibility as a value and norm on the team [42]. While most studies with people with disabilities report on user groups with similar impairments and the researchers are presumed nondisabled, this growing body of work, to which we contribute, concerns intersecting needs and power dynamics.

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 [70]. 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” [18]. 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 [13]. Similarly, high fidelity prototyping tools useful in producing study materials render inaccessible outputs

[41]. 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 [69]. Finally, certain artifacts (such as data visualizations) which are crucial to communicating research are pervasively inaccessible [54].

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” [31], and Chua highlighted the need for frequent accommodations updates [11]. Shinohara et al. found similar trends, which they referred to as “inequitable access” [55]. Even if a student had formal accommodations, they were often insufficient, necessitating what Jain *et al.* called “uncharted accommodations” [31]. 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 [55].

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 and our supplementary materials, may increase adoption of such methods.

2.3 Theoretical Grounding

This paper is grounded in theoretical concepts developed within critical disability studies and activism. Specifically, we draw on crip time and interdependence. Crip time refers to a common experience among disabled communities that life rarely moves linearly or quickly. However, such expectations are often imposed onto chronically ill, neurodivergent, and disabled people. Instead, they recognize how crip time “bends clocks” by slowing down, stopping, or repeating, and recognizing that people’s paces rarely, if ever, match [34]. Next, interdependence emphasizes access work as occurring within a web of “relationships where we are all valued and have things to offer,” [46]. Interdependence opens up modes of thinking about accessibility that aren’t relegated to procedurally remediating disability deficits, but explore communal, rather than solely individual, solutions. These concepts guide our unpacking and reimagining of accessible methods. With crip time, we can question the expected ordering and pacing of phases in a research study and the productivity expectations of facilitators and participants. With interdependence, we can humanize the logistics of planning and executing studies. For example, by understanding research through the relationships, negotiations and ways we may care for

each other, we might establish access as a norm and collective responsibility in research spaces.

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 [40, 49, 72] 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 bodyminds² 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 research³. 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 1

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

²According 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.” [29]

³We 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).

of the various activities they facilitated and to share desired changes which may address them.

3.1 Data Analysis

Six authors analyzed the interview transcripts, which followed a thematic coding process [5, 6]. 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.

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

Table 1: Aggregated participant demographic and role information.

Role		Self-reported disability identity		Self-reported race	
Community org.	4	Autism	2	Asian	5
Researcher	13	Blind or low vision	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				

reporting that may help readers replicate similar studies accessibly and to communicate how access remained central throughout our process.

4 FINDINGS

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 4.2. 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.

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.

4.1 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 2. We include both participant and facilitator considerations, when applicable, in each subsection, as we are committed to not assuming facilitators are nondisabled.

4.1.1 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 [1, 3, 17, 29, 39, 51, 57, 58, 64]. 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 paper; see: [29, 40]. Through a variety of means, interviewees allocated time to learn about their communities of focus and how to best support them in studies.

4.1.2 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

Table 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.”
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].”
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.”
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.”
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.’”

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.

4.1.3 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 fliers 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:

“Not 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.

4.1.4 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 [27, 43].

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.

4.1.5 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 non-trivial 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.

4.1.6 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.

4.1.7 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 translation⁴ 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.

4.1.8 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 [35]. When accessibility conflicted with standard research methods, interviewees recognized the tradeoffs but worked to prioritize 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

⁴For more information on plain language translation, look at [onlineresources](#).

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.

4.1.9 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*) [41] 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 [13, 31], 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 [55].

4.1.10 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.

4.1.11 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.

4.2 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.

4.2.1 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 familiar providers with whom he had established rapport, as those familiar with his

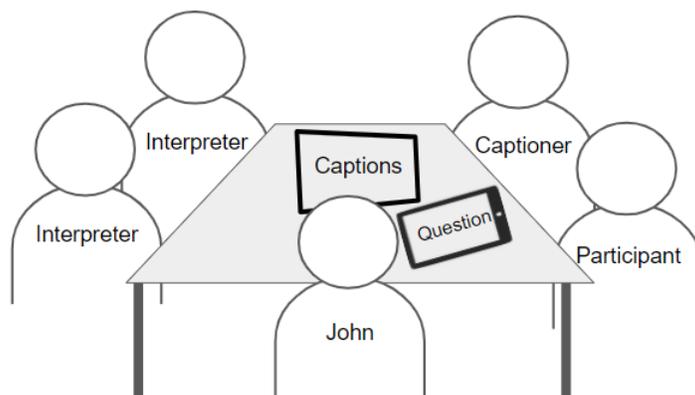


Figure 1: A diagram of John’s setup when interviewing DHH participants. John thoughtfully organized the space to ensure sightlines between himself and his captioner, himself and the participant, his participant and the interpreters, and himself and his participant to the tablet with interview questions. This diagram was created and shared with John’s permission and feedback.

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 [53]). 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.

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

“We were able to take slates and styluses⁵, Dymo⁶ tape . . . 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.

4.2.3 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

⁵A slateandstylus can be used to write in braille.

⁶Dymotape is adhesive tape that can be embossed with braille.

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 research in in-person DeafSpace⁷ [19, 74] 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 video-conferencing 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.

4.2.4 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 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* [34], helped Heather*, Yuzu, and others to run accessible studies [16, 33, 53]. 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.

4.3 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.

4.3.1 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 [46] 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."

⁷A socio-architectural movement that seeks to shape the built environment to match Deaf cultural norms (e.g., supporting ASL and visual communication).

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 lighthearted 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.

4.3.2 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 [46] 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.

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 [14, 37, 50, 53, 61]. 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.

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 [4]. 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 [70]. 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 [22, 36, 47, 61, 65, 67].

Second, we suggest that trainings teach researchers to incorporate microethics, or the ethics of small-scale interactions [60], 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 [7]. 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 [67, 68]. 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 [45, 61]. 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 [53] invite clarity and

reflection that could further build and branch out from philosophies of slow HCI [48]. While people with disabilities should be welcomed into existing activities, access work has the potential to distill new methods [18], 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 [12, 40], 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.

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 [13, 31, 41]. 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* [8, 75]. 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.

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 Deaf-Blind. 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 paper 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

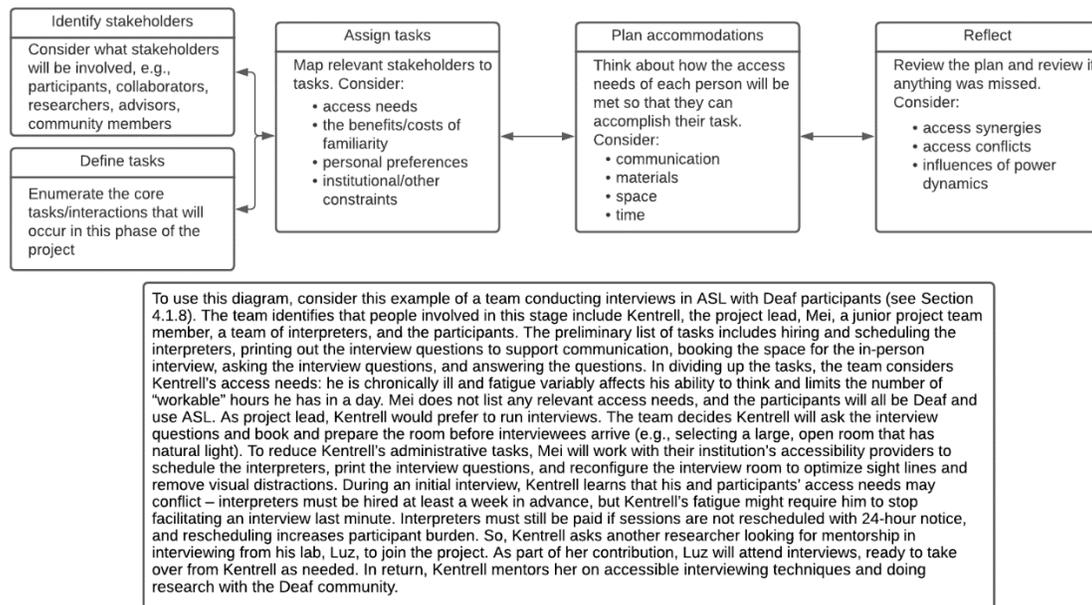


Figure 2: A flow chart that can be applied to plan how to address the access needs of each stakeholder for any stage of the research process outlined in Section 4.1, along with an example application of this workflow.

explore a more complete range of accessible options (e.g., reconfiguring and testing furniture arrangements (John), delegating some participant communications to a colleague (Zack*)) [42].

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 [46]. 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).

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 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 [13, 70] 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 [31, 55, 56]. 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 [24] Project Sidewalk [52, 76] and PISSAR (People In Search of Safe and Accessible Restrooms) [66] 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.

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 [7, 40, 67]. 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. Additionally, taking up Heather's and prior work's [69] 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.

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.

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REFERENCES

- [1] AccessSIGCHI. 2020. Accessible Remote Attendance. *AccessSIGCHI*. Retrieved December 13, 2021 from <https://accesssigchi.com/accessible-remote-attendance/>
- [2] H. K. Beecher. 2001. Ethics and clinical research. 1966. *Bull World Health Organ* 79, 4 (2001), 367–372.
- [3] Cynthia L. Bennett, Abigale Stangl, Alexa F. Siu, and Joshua A. Miele. 2019. Making Nonvisually: Lessons from the Field. In *Adjunct Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '19)*, Association for Computing Machinery, New York, NY, USA, 279–285. DOI:<https://doi.org/10.1145/3308561.3355619>
- [4] Stacy M. Branham and Shaun K. Kane. 2015. The Invisible Work of Accessibility: How Blind Employees Manage Accessibility in Mixed-Ability Workplaces. In *Proceedings of the 17th International ACM SIGACCESS Conference on Computers & Accessibility (ASSETS '15)*, Association for Computing Machinery, New York, NY, USA, 163–171. DOI:<https://doi.org/10.1145/2700648.2809864>
- [5] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 2 (January 2006), 77–101. DOI:<https://doi.org/10.1191/1478088706qp063oa>
- [6] Virginia Braun and Victoria Clarke. 2019. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health* 11, 4 (August 2019), 589–597. DOI:<https://doi.org/10.1080/2159676X.2019.1628806>
- [7] Emeline Brulé and Katta Spiel. 2019. Negotiating Gender and Disability Identities in Participatory Design. In *Proceedings of the 9th International Conference on Communities & Technologies - Transforming Communities (C&T '19)*, Association for Computing Machinery, New York, NY, USA, 218–227. DOI:<https://doi.org/10.1145/3328320.3328369>
- [8] Margaret Burnett. 2021. From GenderMag to InclusiveMag: A Journey for University IT. In *Proceedings of the ACM SIGUCCS Annual Conference (SIGUCCS '21)*, Association for Computing Machinery, New York, NY, USA, 1–2. DOI:<https://doi.org/10.1145/3419944.3440725>
- [9] Sabrina Burtscher and Katta Spiel. 2020. "But where would I even start?": developing (gender) sensitivity in HCI research and practice. In *Proceedings of the Conference on Mensch und Computer (MuC '20)*, Association for Computing Machinery, New York, NY, USA, 431–441. DOI:<https://doi.org/10.1145/3404983.3405510>
- [10] Mel Chua and Robin S. Adams. 2014. Using realtime transcription to do member-checking during interviews. In *2014 IEEE Frontiers in Education Conference (FIE) Proceedings*, 1–3. DOI:<https://doi.org/10.1109/FIE.2014.7044251>
- [11] Mel Chua, Brittany Ray, and Lynn Andrea Stein. 2017. A behind-the-scenes look at access setup: A case study of the deaf professional / designated interpreter model in engineering education research. In *2017 IEEE Frontiers in Education Conference (FIE) Adjunct Proceedings*, 1–9. DOI:<https://doi.org/10.1109/FIE.2017.8190512>
- [12] Kara Pernice Coyne and Jakob Nielsen. 2001. How to conduct usability evaluations for accessibility: Methodology guidelines for testing websites and intranets with users who use assistive technology. Retrieved from <http://www.NNgroup.com/reports/accessibility/testing>
- [13] Maitraye Das, Darren Gergle, and Anne Marie Piper. 2019. "It doesn't win you friends": Understanding Accessibility in Collaborative Writing for People with Vision Impairments. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (November 2019), 191:1-191:26. DOI:<https://doi.org/10.1145/3359293>
- [14] A. Dickinson, J. Arnott, and S. Prior. 2007. Methods for human - computer interaction research with older people. *Behaviour & Information Technology* 26, 4 (July 2007), 343–352. DOI:<https://doi.org/10.1080/01449290601176948>
- [15] Catherine D'Ignazio and Lauren Klein. 2020. 4. "What Gets Counted Counts." *Data Feminism* (March 2020). Retrieved September 9, 2021 from <https://datafeminism.mitpress.mit.edu/pub/h1w0nbqj/release/2>
- [16] Katja Dindar, Anne Lindblom, and Eija Käinä. 2017. The construction of communicative (in)competence in autism: a focus on methodological decisions. *Disability & Society* 32, 6 (July 2017), 868–891. DOI:<https://doi.org/10.1080/09687599.2017.1329709>
- [17] DO-IT. Making a Makerspace? Guidelines for Accessibility and Universal Design. Retrieved December 13, 2021 from <https://www.washington.edu/doit/making-makerspace-guidelines-accessibility-and-universal-design>
- [18] Jay Timothy Dolmage. Introduction The Approach from Academic Ableism: Disability and Higher Education on JSTOR. Retrieved September 8, 2021 from <https://www.jstor.org/stable/j.ctv33d50.3>
- [19] Claire Edwards and Gill Harold. 2014. DeafSpace and the principles of universal design. *Disability and Rehabilitation* 36, 16 (August 2014), 1350–1359. DOI:<https://doi.org/10.3109/09638288.2014.913710>
- [20] Ruth R. Faden and Tom L. Beauchamp. 1986. *A History and Theory of Informed Consent*. Oxford University Press.
- [21] Christopher Frauenberger, Julia Makhaeva, and Katta Spiel. 2016. Designing Smart Objects with Autistic Children: Four Design Exposés. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*, Association for Computing Machinery, New York, NY, USA, 130–139. DOI:<https://doi.org/10.1145/2858036.2858050>
- [22] Christopher Frauenberger, Julia Makhaeva, and Katta Spiel. 2017. Blending Methods: Developing Participatory Design Sessions for Autistic Children. In *Proceedings of the 2017 Conference on Interaction Design and Children (IDC '17)*, Association for Computing Machinery, New York, NY, USA, 39–49. DOI:<https://doi.org/10.1145/3078072.3079727>
- [23] Julia Galliers, Stephanie Wilson, Abi Roper, Naomi Cocks, Jane Marshall, Sam Muscroft, and Tim Pring. 2012. Words are not enough: empowering people with aphasia in the design process. In *Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1 (PDC '12)*, Association for Computing Machinery, New York, NY, USA, 51–60. DOI:<https://doi.org/10.1145/2347635.2347643>
- [24] Aimi Hamraie. 2016. Mapping Access. Retrieved September 9, 2021 from <https://aimihamraie.wordpress.com/socio-spatial-practice-2/mapping-access/>
- [25] Christina Harrington, Sheena Erete, and Anne Marie Piper. 2019. Deconstructing Community-Based Collaborative Design: Towards More Equitable Participatory Design Engagements. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW (November 2019), 216:1-216:25. DOI:<https://doi.org/10.1145/3359318>
- [26] Megan Hofmann, Jeffrey Harris, Scott E. Hudson, and Jennifer Mankoff. 2016. Helping Hands: Requirements for a Prototyping Methodology for Upper-limb Prosthetics Users. In *Proceedings of the 2016 CHI Conference on Human Factors in*

- Computing Systems*. Association for Computing Machinery, New York, NY, USA, 1769–1780. Retrieved September 8, 2021 from <http://doi.org/10.1145/2858036.2858340>
- [27] Megan Hofmann, Devva Kasnitz, Jennifer Mankoff, and Cynthia L Bennett. 2020. Living Disability Theory: Reflections on Access, Research, and Design. In *Proceedings of the 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20)*, Association for Computing Machinery, New York, NY, USA, 1–13. DOI:<https://doi.org/10.1145/3373625.3416996>
- [28] T. Iacono and R. Carling-Jenkins. 2012. The human rights context for ethical requirements for involving people with intellectual disability in medical research. *Journal of Intellectual Disability Research* 56, 11 (2012), 1122–1132. DOI:<https://doi.org/10.1111/j.1365-2788.2012.01617.x>
- [29] Sins Invalid. *Skin, Tooth, and Bone: A Disability Justice Primer*. Retrieved September 8, 2021 from <https://www.sinsinvalid.org/disability-justice-primer>
- [30] Dhruv Jain, Audrey Desjardins, Leah Findlater, and Jon E. Froehlich. 2019. Autoethnography of a Hard of Hearing Traveler. In *Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '19)*, Association for Computing Machinery, New York, NY, USA, 236–248. DOI:<https://doi.org/10.1145/3308561.3353800>
- [31] Dhruv Jain, Venkatesh Potluri, and Ather Sharif. 2020. Navigating Graduate School with a Disability. In *Proceedings of the 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20)*, Association for Computing Machinery, New York, NY, USA, 1–11. DOI:<https://doi.org/10.1145/3373625.3416986>
- [32] Ben Jelen, Anne Freeman, Mina Narayanan, Kate M. Sanders, James Clawson, and Katie A. Siek. 2019. Crafted: Engaging Older Adults in Making through a Craft-Based Toolkit System. In *Proceedings of the 13th International Conference on Tangible, Embedded, and Embodied Interaction (TEI '19)*, Association for Computing Machinery, New York, NY, USA, 577–587. DOI:<https://doi.org/10.1145/3294109.3295636>
- [33] Stefan Johansson, Jan Gulliksen, and Ann Lantz. 2015. User Participation When Users have Mental and Cognitive Disabilities. In *Proceedings of the 17th International ACM SIGACCESS Conference on Computers & Accessibility (ASSETS '15)*, Association for Computing Machinery, Lisbon, Portugal, 69–76. DOI:<https://doi.org/10.1145/2700648.2809849>
- [34] Alison Kafer. 2013. *Feminist, Queer, Crip*. Indiana University Press.
- [35] Shaun K. Kane and Caroline Galbraith. Design Guidelines for Creating Voting Technology for Adults with Aphasia. Retrieved from <http://elections.itif.org/wp-content/uploads/AVTI-006-Kane-2013.pdf>
- [36] Shaun K. Kane, Amy Hurst, Erin Buehler, Patrick A. Carrington, and Michele A. Williams. 2014. Collaboratively designing assistive technology. *Interactions* 21, 2 (March 2014), 78–81. DOI:<https://doi.org/10.1145/2566462>
- [37] Shaun K. Kane, Barbara Linam-Church, Kyle Althoff, and Denise McCall. 2012. What we talk about: designing a context-aware communication tool for people with aphasia. In *Proceedings of the 14th international ACM SIGACCESS conference on Computers and accessibility (ASSETS '12)*, Association for Computing Machinery, New York, NY, USA, 49–56. DOI:<https://doi.org/10.1145/2384916.2384926>
- [38] Shenila Khoja-Moolji. 2016. Doing the ‘work of hearing’: girls’ voices in transnational educational development campaigns. *Compare: A Journal of Comparative and International Education* 46, 5 (September 2016), 745–763. DOI:<https://doi.org/10.1080/03057925.2015.1084582>
- [39] Raja S. Kushalnagar and Christian Vogler. 2020. Teleconference Accessibility and Guidelines for Deaf and Hard of Hearing Users. In *Adjunct Proceedings of the 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20)*, Association for Computing Machinery, New York, NY, USA, 1–6. DOI:<https://doi.org/10.1145/3373625.3417299>
- [40] Jonathan Lazar, Jinjuan Heidi, and Hochheiser. 2017. Working with research participants with disabilities. In *Research Methods in Human-Computer Interaction (Second)*. Morgan Kaufmann.
- [41] Junchen Li, Garreth W. Tigwell, and Kristen Shinohara. 2021. Accessibility of High-Fidelity Prototyping Tools. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*, Association for Computing Machinery, New York, NY, USA, 1–17. Retrieved September 8, 2021 from <http://doi.org/10.1145/3411764.3445520>
- [42] Kelly Mack, Maitraye Das, Dhruv Jain, Danielle Bragg, John Tang, Andrew Begel, Erin Beneteau, Josh Urban Davis, Abraham Glasser, Joon Sung Park, and Venkatesh Potluri. Mixed Abilities and Varied Experiences: a group autoethnography of a virtual summer internship. In *Proceedings of the 23rd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '21)*, Association for Computing Machinery, New York, NY, USA.
- [43] Kelly Mack, Emma McDonnell, Dhruv Jain, Lucy Lu Wang, Jon E. Froehlich, and Leah Findlater. 2021. What Do We Mean by “Accessibility Research”? A Literature Survey of Accessibility Papers in CHI and ASSETS from 1994 to 2019. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*, Association for Computing Machinery, New York, NY, USA, 1–18. Retrieved December 17, 2021 from <http://doi.org/10.1145/3411764.3445412>
- [44] Oussama Metatla, Nick Bryan-Kinns, Tony Stockman, and Fiore Martin. 2015. Designing with and for people living with visual impairments: audio-tactile mock-ups, audio diaries and participatory prototyping. *CoDesign* 11, 1 (January 2015), 35–48. DOI:<https://doi.org/10.1080/15710882.2015.1007877>
- [45] Oussama Metatla and Clare Cullen. 2018. “Bursting the Assistance Bubble”: Designing Inclusive Technology with Children with Mixed Visual Abilities. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (CHI '18)*, Association for Computing Machinery, Montreal QC, Canada, 1–14. DOI:<https://doi.org/10.1145/3173574.3173920>
- [46] Mia Mingus. 2017. Access Intimacy, Interdependence and Disability Justice. *Leaving Evidence*. Retrieved September 8, 2021 from <https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/>
- [47] Rebecca Monteleone. 2018. Beyond Participation: Empowering People with Disabilities in Research and Design. *Technology & Innovation* 20, 1–2 (November 2018), 133–139. DOI:<https://doi.org/10.121300/20.1-2.2018.133>
- [48] Kai A Olsen and Alessio Malizia. 2012. Invisible Stable Interfaces. *interfaces*.
- [49] Judith S. Olson and Wendy A. Kellogg (Eds.). 2014. *Ways of Knowing in HCI*. Springer-Verlag, New York. DOI:<https://doi.org/10.1007/978-1-4939-0378-8>
- [50] Venkatesh Potluri, Tadashi E Grindeland, Jon E. Froehlich, and Jennifer Mankoff. 2021. Examining Visual Semantic Understanding in Blind and Low-Vision Technology Users. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 1–14. Retrieved September 8, 2021 from <http://doi.org/10.1145/3411764.3445040>
- [51] Abi Roper, Ian Davey, Stephanie Wilson, Timothy Neate, Jane Marshall, and Brian Grellmann. 2018. Usability Testing - An Aphasia Perspective. In *Proceedings of the 20th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '18)*, Association for Computing Machinery, New York, NY, USA, 102–106. DOI:<https://doi.org/10.1145/3234695.3241481>
- [52] Manaswi Saha, Michael Saugstad, Hanuma Teja Maddali, Aileen Zeng, Ryan Holland, Steven Bower, Aditya Dash, Sage Chen, Anthony Li, Kotaro Hara, and Jon Froehlich. 2019. Project Sidewalk: A Web-based Crowdsourcing Tool for Collecting Sidewalk Accessibility Data At Scale. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. Association for Computing Machinery, New York, NY, USA, 1–14. Retrieved September 9, 2021 from <http://doi.org/10.1145/3290605.3300292>
- [53] Juliet Scott-Barrett, Katie Cebula, and Lani Florian. 2019. Listening to young people with autism: learning from researcher experiences. *International Journal of Research & Method in Education* 42, 2 (March 2019), 163–184. DOI:<https://doi.org/10.1080/1743727X.2018.1462791>
- [54] Ather Sharif, Sanjana S Chintalapati, Jacob O. Wobbrock, and Katharina Reinecke. Understanding Screen-Reader Users’ Experiences with Online Data Visualizations. In *Proceedings of the 23rd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '21)*, Association for Computing Machinery, New York, NY, USA.
- [55] Kristen Shinohara, Michael McQuaid, and Nayeri Jacobo. 2020. Access Differential and Inequitable Access: Inaccessibility for Doctoral Students in Computing. In *The 22nd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '20)*, Association for Computing Machinery, New York, NY, USA, 1–12. DOI:<https://doi.org/10.1145/3373625.3416989>
- [56] Kristen Shinohara, Mick McQuaid, and Nayeri Jacobo. 2021. The Burden of Survival: How Doctoral Students in Computing Bridge the Chasm of Inaccessibility. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*, Association for Computing Machinery, New York, NY, USA, 1–13. Retrieved September 8, 2021 from <http://doi.org/10.1145/3411764.3445277>
- [57] SIGACCESS. Accessible Writing Guide. Retrieved December 13, 2021 from <http://www.sigaccess.org/welcome-to-sigaccess/resources/accessible-writing-guide/>
- [58] SIGACCESS. Accessible Conference Guide. Retrieved December 13, 2021 from <http://www.sigaccess.org/welcome-to-sigaccess/resources/accessible-conference-guide/>
- [59] Alexa F. Siu, Son Kim, Joshua A. Miele, and Sean Follmer. 2019. shapeCAD: An Accessible 3D Modelling Workflow for the Blind and Visually-Impaired Via 2.5D Shape Displays. In *Proceedings of the 21st International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '19)*, Association for Computing Machinery, New York, NY, USA, 342–354. DOI:<https://doi.org/10.1145/3308561.3353782>
- [60] Katta Spiel, Emeline Brulé, Christopher Frauenberger, Gilles Bailly, and Geraldine Fitzpatrick. 2018. Micro-ethics for participatory design with marginalised children. In *Proceedings of the 15th Participatory Design Conference: Full Papers - Volume 1 (PDC '18)*, Association for Computing Machinery, New York, NY, USA, 1–12. DOI:<https://doi.org/10.1145/3210586.3210603>
- [61] Katta Spiel, Christopher Frauenberger, Os Keyes, and Geraldine Fitzpatrick. 2019. Agency of Autistic Children in Technology Research—A Critical Literature Review. *ACM Trans. Comput.-Hum. Interact.* 26, 6 (November 2019), 38:1–38:40. DOI:<https://doi.org/10.1145/3344919>
- [62] Katta Spiel, Oliver L. Haimson, and Danielle Lottridge. 2019. How to do better with gender on surveys: a guide for HCI researchers. *Interactions* 26, 4 (June 2019), 62–65. DOI:<https://doi.org/10.1145/3338283>
- [63] Kate Stephens, Matthew Butler, Leona M Holloway, Catagay Goncu, and Kim Marriott. 2020. Smooth Sailing? Autoethnography of Recreational Travel by a Blind Person. In *Proceedings of the 22nd International ACM SIGACCESS Conference on*

- Computers and Accessibility* (ASSETS '20), Association for Computing Machinery, New York, NY, USA, 1–12. DOI:<https://doi.org/10.1145/3373625.3417011>
- [64] Amelie Unger, Dieter P. Wallach, and Nicole Jochems. 2021. Lost in Translation: Challenges and Barriers to Sign Language-Accessible User Research. In *The 23rd International ACM SIGACCESS Conference on Computers and Accessibility*. Association for Computing Machinery, New York, NY, USA, 1–5. Retrieved December 13, 2021 from <http://doi.org/10.1145/3441852.3476473>
- [65] Stephanie Valencia, Mark Steidl, Michael Rivera, Cynthia Bennett, Jeffrey Bigham, and Henny Admoni. 2021. Aided Nonverbal Communication through Physical Expressive Objects. In *Proceedings of the 23rd International ACM SIGACCESS Conference on Computers and Accessibility* (ASSETS '21), Association for Computing Machinery, New York, NY, USA, 1–11. DOI:<https://doi.org/10.1145/3441852.3471228>
- [66] Isaac West. 2010. PISSAR's Critically Queer and Disabled Politics. *Communication and Critical/Cultural Studies* 7, 2 (June 2010), 156–175. DOI:<https://doi.org/10.1080/14791421003759174>
- [67] Rua Williams and Juan Gilbert. 2019. “Nothing About Us Without Us” Transforming Participatory Research and Ethics in Human Systems Engineering. . 113–134. DOI:<https://doi.org/10.1201/9780429425905-9>
- [68] Rua M. Williams and Juan E. Gilbert. 2019. Cyborg Perspectives on Computing Research Reform. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems* (CHI EA '19), Association for Computing Machinery, New York, NY, USA, 1–11. DOI:<https://doi.org/10.1145/3290607.3310421>
- [69] Zeynep Yildiz and Ozge Subasi. 2020. Disabled and Design Researcher: An Unexpected Relationship? In *Companion Publication of the 2020 ACM Designing Interactive Systems Conference* (DIS '20 Companion), Association for Computing Machinery, New York, NY, USA, 61–66. DOI:<https://doi.org/10.1145/3393914.3395861>
- [70] Anon Ymous, Katta Spiel, Os Keyes, Rua M. Williams, Judith Good, Eva Hornecker, and Cynthia L. Bennett. 2020. “I am just terrified of my future” – Epistemic Violence in Disability Related Technology Research. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems* (CHI EA '20), Association for Computing Machinery, New York, NY, USA, 1–16. DOI:<https://doi.org/10.1145/3334480.3381828>
- [71] AccessSIGCHI. *AccessSIGCHI*. Retrieved September 9, 2021 from <https://accesssigchi.com/>
- [72] Methods. *usability.gov: Improving the User Experience*. Retrieved September 8, 2021 from <https://www.usability.gov/how-to-and-tools/methods/index.html>
- [73] HCI/UX research: what methods do we use? – Lisa Koeman – blog. Retrieved June 27, 2020 from <https://lisakoeman.nl/blog/hci-ux-research-what-methods-do-we-use/>
- [74] Deafspace. *Gallaudet University*. Retrieved August 31, 2021 from <https://www.gallaudet.edu/campus-design-and-planning/deafspace/>
- [75] GenderMag. Retrieved September 8, 2021 from <https://gendermag.org/>
- [76] Project Sidewalk. Retrieved September 9, 2021 from <https://sidewalk-sea.cs.washington.edu/http://sidewalk.umiacs.umd.edu>