

# Tackling the Lack of a Practical Guide in Disability-Centered Research

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## ABSTRACT

Accessibility research strives to develop technology that is useful for disabled people, but the research processes that we engage in do not always center disabled people in a way that allows us to shape artifacts so that they benefit disabled communities. In this workshop, we want to address core questions that are relevant in this context: How can research questions be defined in a way that shares power between research teams and technology users? How should research processes be designed to be broadly accessible for disabled people? And what are equitable ways of summarizing and sharing research findings in a way that allows disabled communities to critically appraise findings with us? Through discussion among all attendees, we want to develop a practical guide in disability-centered research that will be made available and further developed as a community resource when engaging in accessibility research.

## CCS CONCEPTS

• **Human-centered computing** → **Accessibility theory, concepts and paradigms; Accessibility design and evaluation methods.**

## KEYWORDS

Access, Disability Justice, Research Methods

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## 1 INTRODUCTION AND BACKGROUND

Accessibility research routinely makes assumptions about disabled people and their needs, abilities, and wishes. While the Human-Computer Interaction and Accessibility research communities promote human-centered and participatory design approaches, there are many cases in which power remains within research teams, and is not adequately shared with disabled participants [3]. In the past, this has led to instances in which research has struggled to understand disability [11], creating irrelevant technical artifacts for which Jackson has coined the term “disability dongle” [15], and producing research outcomes that systematically harm the very communities that accessibility research claims to support [20, 25, 26]. In this context, our community has long appreciated the value of Disability Studies as a lens to critically examine research efforts in accessibility (e.g., [10, 11, 16, 17]). Likewise, there has been a call to adopt disability justice as a framework to shape our work, thereby centering the needs of disabled communities [18] and constructively engaging with biases [23].

However—and despite these insights—our research communities tend to fail to engage in structured dialogue as to how researchers should practically engage with issues around power and bias when conducting accessibility research. Despite emerging scholarship producing critically informed guidance for participatory reform in HCI [4, 6, 16], this work remains marginalized within the discipline, in part due to the intersectional identities of the writers and their junior status [26]. Likewise, while there is some community-level advice on surface-level issues (e.g., the SIGACCESS Accessible

Writing Guides [19]), there are simultaneously prominent examples where these resources were not considered and harmful language prevailed, subsequently proliferating traditional power dynamics in access(ibility) research. There is evidence of research communities producing technological artifacts that prioritize non-disabled perspectives and perpetuate harmful stereotypes (e.g., [8, 21]). Hence, there is a need to provide actionable guidance for research teams that reminds and supports them to engage with fundamental aspects of their work, e.g., critically appraising who formulates research questions and shapes research directions [9, 25], and how author positionality, adopting theoretical lenses, and research methodology affect research outcomes for disabled communities [5].

Building on these considerations, the goal of this workshop is to develop a practical guide that helps accessibility researchers operationalize insights from disability studies and reflective accessibility research, while encouraging our community to critically appraise research positionality to center the perspectives of disabled people, echoing recent calls from disabled communities (e.g., [14]). To this end, we invite broad participation, ranging from early career researchers and persons who have recently entered our field, to more established researchers wishing to reflect upon their past and ongoing research efforts. Through conversation, it is our hope that we can jointly contribute a draft of a community-led guide to support justice-minded access(ibility) research, taking another step in the process of creating a resource that will support all of us in the establishment of research processes that center disabled people.

## 2 WORKSHOP PLANS

A key challenge for this workshop will be to create a safe working environment in which participants can openly share their experiences, difficulties that they encountered, and elements of their research approaches and processes that they wish to improve. We will therefore divide work on the topic in the following three phases.

### 2.1 Phase 1 (Part of our Pre-Workshop Plans)

Before the workshop, we will facilitate asynchronous communication between attendees (using a platform such as Discord) to encourage people to get to know each other in an informal setting. We will use this first phase to gather questions from participants, and will do so in an anonymous format (for example, using a Google form) to account for differences in power. Additionally, we will share participants' workshop submissions at this stage, both in a consolidated format that summarizes main points, and (if approved by each participant), as individual documents.

### 2.2 Phase 2 (Main Part of the Workshop)

We will build on participants' questions and feedback in the second phase, which is a synchronous event at or near the time of the conference, and will be facilitated via Zoom, making use of breakout rooms. It will take place in two two-hour chunks, which will be held on two separate days to leave room for reflection between sessions, and to accommodate different time zones. Overall, this phase will focus on theoretical and reflective engagement with our own perspectives on disability, and practical considerations, reflecting upon how accessibility research is currently carried out, and what can be improved.

The phase will begin with a plenary session that forms a foundation for all participants and introduces key concepts from (critical) Disability Studies (e.g., models of disability, and relevant structural prejudices such as academic ableism and its manifestation in research [7, 9, 25]). Leveraging a mixture of work in small groups (3-4 attendees plus at least one organizer) and summarizing plenary sessions, we then seek to address the following topics, with priorities being set in conversation with attendees:

**2.2.1 Reorienting questions to explore our own positionality.** In this activity, all participants including the organizers will self-reflect and answer a set of challenging questions privately (without the intention of sharing the answers with others). These questions will assist us in uncovering the things we don't know we don't know. Some examples include: "How do you describe your research participants in your publications? Would you describe them that way if they were in the room with you?", and "How did you decide your research questions? Did you talk to participants before these questions were decided?" These questions will help our attendees orient themselves to the work of questioning our individual biases, ableism and the (lack of) engagement with disabled communities. Who are we, what privilege do we hold, and how does this influence our work? Who is currently represented in our research community, who is not (e.g., working with disabled people vs. working with not-for-profit organizations, disability and accessibility professionals, caregivers? What about involving researchers and sites outside of the Global North (e.g., [2])?

**2.2.2 Guidance on developing research questions and defining foundations for research.** We will then discuss questions such as: who should be involved in formulating research questions and how can power be shared? What are practical steps that can be taken to ensure technology benefits disabled people? What theoretical foundation is adequate for intervention-focused research? How can models of disability help shape research questions? In groups, participants will choose a publication from the authors in their breakout room. Using the Counterfactual Principles [24] as a guide, participants will re-imagine how interventions could be reoriented to center community desires and participant testimony, and will reflect upon the impact of leveraging theory and interventional techniques from other fields on the positionality of technology that we develop. This activity will assist attendees in developing new skills for research agenda development.

**2.2.3 Choosing adequate research methodology and creating accessible research settings.** In groups, participants will discuss their own publications or research projects in their breakout room to engage in Participatory Evaluation. Together, they will discuss how the research protocol impacts participatory agency of participants, using the PEACE framework [22] as a guide. This activity will engage attendees in thoughtful self-reflection and inspire new priorities in protocol development. Building on this activity, participants will identify a time that a research participant was excluded because of some accessibility barrier in the research protocol. From this scenario, groups will imagine ways that a protocol could be adapted such that overlapping disabilities or intersectional identities will not constitute an exclusion criteria for participants. The attendees will use the work of Mack et al. [16] and Williams and Gilbert [25]

as a guide, and we will build upon considerations within the SIGACCESS community regarding inclusive remote participation [1]. We will further work with resources that have been prepared by disabled communities that address accessible events, and that are not commonly acknowledged in academia, for example, [13], and tailored guidance for accessible research processes (e.g., [12]). Here, we will explore how existing knowledge can inform the research process.

**2.2.4 Appropriately reporting research findings.** Participants will work together to reflect on how they share how the research was conducted. We will ask them to reflect on the following questions. How can research be presented in a way that moves beyond confirmatory paradigms and also communicates uncertainties, participants expressing doubts, or indicating non-use of technology? How does language reflect power when reporting findings? What language should be used when discussing disability? How can research teams involve participants in the review of findings, and how can outcomes be shared with the communities that they concern? What responsibility does the academic community have to engage with disabled communities in the critical appraisal of the results that the academy produces? How should authors report on the accessibility considerations that they provided in their studies?

Groups will be carefully constructed, accounting for participant preferences and power dynamics (e.g., whether someone is a PhD student or tenured faculty), and will be guided by at least one member of the organizing team. Throughout this phase, we will track discussions and solicit participant input using Google forms. We have chosen this option as it is one that we expect to be accessible to a broad range of participants. Additionally, the organizers will prepare a document that is structured along the research process (e.g., formulation of research questions, design of research methodology), and will be used to systematically track practical guidance that emerges from discussion in smaller groups. Throughout the workshop, we will use moments with the plenary to share, discuss, and adjust these outcomes with participants.

### 2.3 Phase 3 (After the Workshop)

We will use our shared platform to summarize and refine guidance that was crafted during the second part of the workshop. Interested participants are welcome to work with the organizing team to create a community resource that summarizes guidance for accessibility research that centers disabled people. In the short term, we will share the resulting document on the workshop website, and we plan to submit it to the SIGACCESS newsletter. In the medium term, we plan to work with all workshop participants toward an article for publication in *Interactions*, or—if comprehensive enough—*TACCESS*, and we hope to turn our resource into a course that can be offered at larger conferences such as CHI. We acknowledge that such an effort will remain an ongoing work in progress, and we are committed to revisiting the topic (e.g., in another ASSETS workshop).

## 3 DIVERSITY AND INCLUSION CONSIDERATIONS

We will promote diversity and inclusion at our workshop in the following ways: We will clearly communicate expectations and workshop structure to participants, and will make important choices jointly (e.g., topics, frequency of breaks). We will opt for a workshop format that accounts for different access needs among participants, combining synchronous and asynchronous forms of interaction, each with regular breaks. For participants who prefer to exclusively engage in asynchronous activities, we will record and share accessible videos of the plenary parts of the synchronous event, will share our central document with guidance for asynchronous comments, and will create a dedicated channel on our shared platform for asynchronous attendance. Synchronous and asynchronous group conversations and activities will always be facilitated by a member of the organizing team. Groups will be put together in advance of the synchronous event, and we will account for power structures. Participants not comfortable in a specific group are allowed to join another one of their choosing. In terms of platforms and software, we have made suggestions but will negotiate further access needs with participants as we recognize that each tool comes with specific inaccessibilities. The synchronous portion of the workshop will include sign language translation and captioning, and we will encourage participants to share further access needs with us.

Additionally, we will make an effort to reach out to broad communities who may be interested in engaging with our workshop, ensuring that currently underrepresented groups in accessibility research are encouraged to join (also see Pre-Workshop Plans, section 6). We believe that having a diverse group of attendees will be key to creating an atmosphere in which accessibility research can be discussed from different perspectives. Here, we will make clear that all participants are expected to communicate respectfully and make room for each other, including each other's opinions, creating a space for shared reflection. Finally, we have outlined in our *Call for Papers* (section 7) that we will accept multiple submission types and formats, reducing some typical barriers associated with academic publishing.

## 4 ORGANIZERS

**Emma McDonnell** is a final-year PhD candidate in Human Centered Design and Engineering at the University of Washington. Her research focuses on how accessible communication tools could be designed to better share access labor with hearing and nondisabled conversation partners, motivated by disability justice values of collective access and interdependence.

**Kelly Avery Mack** is a final year PhD Candidate in the Paul G. Allen School of Computer Science and Engineering at the University of Washington. Their work focuses on increasing representation of disability in digital technologies (e.g., avatars, AI systems) and broadening who is represented in accessibility research (e.g., people who are chronically ill, have mental health conditions, or are neurodiverse).

**Kathrin Gerling** is a Professor of Human-Computer Interaction and Accessibility at KIT, Germany, and a neurodivergent person. Her work aims to explore how disabled people leverage technology

in the context of work and leisure, and she is interested in how accessible emerging technologies can contribute to our wellbeing.

**Katta Spiel** is an Assistant Professor of Critical Access in Embodied Computing at the HCI Group of TU Wien, where they work on the intersection of Computer Science, Design and Cultural Studies. They research marginalized perspectives on technologies to inform interaction design and engineering in critical ways, so they may account for the diverse realities they operate in and in collaboration with neurodivergent and/or nonbinary peers.

**Cynthia (Cindy) Bennett** is a senior research scientist in Google's Responsible AI organization. Her research concerns making technology-mediated experiences, such as those leveraging generative AI, accessible to and representative of people with disabilities while mitigating harmful applications. She is also a disabled woman scholar committed to raising participation of people with disabilities in computing fields.

**Robin N. Brewer** is an Assistant Professor in the School of Information at the University of Michigan. She studies the role of power in care relationships and care technologies with older adults and designs tools for non-visual technology access with older adults and people with disabilities.

**Rua M. Williams** is an Assistant Professor of User Experience Design at Purdue University. They are a Just Tech Fellow with the Social Science Research Council. Their research centers disabled ontology and epistemology in the analysis and critique of existing sociotechnical inequities and the design and development of new resistant sociotechnical formations.

**Garreth W. Tigwell** is an Assistant Professor in the School of Information at the Rochester Institute of Technology. His research primarily focuses on improving the accessibility of digital spaces by understanding challenges that designers face and how to support them in utilizing accessible design.

## 5 WEBSITE

The website will feature the *Call for Papers*, more detailed explanations regarding the goals of the workshop, guidance on the different submission formats and how to make materials accessible, and an overview of the organizing team. Authors may choose to have their submissions published on the workshop website, but this will not be a requirement particularly for submissions that are more personal in nature. After the workshop, we will include an academic summary and a plain language summary on our website. The website can be reached via <http://assets2023guide.mere.st>.

## 6 PRE-WORKSHOP PLANS

Our pre-workshop plans include publishing the *Call for Papers* using mailing lists and social media channels that reach the HCI and accessibility research communities. Additionally, we will ensure that the *Call for Papers* is shared with communities that are currently underrepresented in accessibility research, e.g., the HCI across borders group, and we will reach out to our own network of disabled scholars and partner organizations.

Beyond publicizing our workshop in the lead-up to the event, we also envision concrete steps to bring participants together in the lead-up to the event. Please see section 2.1 for these plans, which we consider to be part of our general workshop plan.

## 7 CALL FOR PAPERS

The workshop “Tackling the Lack of a Practical Guide in Disability-Centered Research” aims to explore the opportunity to provide practical guidance for access(ibility) research that centers disabled people. We intend to build on insights from disability studies, critical access research, and disabled communities, seeking to minimize instances in which research is irrelevant or does harm. The overarching goal is to discuss current research approaches, and develop practical recommendations for our research community.

We invite participation from members of our community and beyond who want to reflect on how we engage in research, including those who are new to accessibility research.

Submissions should be a short engagement with the topic, and could be in written format, a video, or another graphical format (please refer to website for details), must be accessible, and should fall into one of the three following categories: (1) Reflective accounts of one's own research, critically examining researcher positionality and how disabled people were (not) included in the research process. (2) A summary of questions that you have with respect to accessibility research that centers disabled people, and an indication of guidance that you would like to receive. This category is particularly suited for people who are new to accessibility research. (3) Experience reports of research participation, or instances in which participation was declined. This category is open to disabled people who have previously taken part in (accessibility) research (or declined to do so).

Submissions are due on Wednesday, September 27th 2023, and can be made via email to [assets2023guide@frimble.net](mailto:assets2023guide@frimble.net).

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