

Designing Through Lived Experience: Reflections on Control, Embodiment, and Social Bias in Accessibility Research

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Abstract

This paper presents an analytic autoethnography of three accessibility research projects, MouseClicker, Virtual Steps, and Simulated Conversations, led by the first author, a disabled researcher with Spinal Muscular Atrophy. Each project emerged from personal need and embodied experience, and together they explore new possibilities in accessible interaction, sensation, and social engagement. Drawing from feminist HCI, crip technoscience, and design justice, we argue that designing through disability is not simply a methodological stance but a form of epistemic resistance. We show how emotional labor, insider knowledge, and lived specificity can generate design insights that challenge normative assumptions about simplicity, generalizability, and what disabled users should want. Our contributions include: (1) documenting three disability-centered design interventions; (2) surfacing cross-cutting themes of agency, emotional labor, and epistemic friction; and (3) offering implications for reframing accessibility research as an inclusive, reflexive, and justice-oriented practice. This report invites the HCI community to recognize lived experience not as anecdotal, but as rigorous situated knowledge essential to equitable design.

CCS Concepts

• **Human-centered computing** → **Accessibility systems and tools; Empirical studies in HCI; Participatory design; Accessibility theory, concepts and paradigms;** • **Social and professional topics** → **People with disabilities.**

Keywords

Accessibility; Disability-centered design; Autoethnography; Emotional labor; Lived experience

ACM Reference Format:

Atieh Taheri, Misha Sra, Patrick Carrington, and Jeffrey P. Bigham. 2025. Designing Through Lived Experience: Reflections on Control, Embodiment,

and Social Bias in Accessibility Research. In *The 27th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '25)*, October 26–29, 2025, Denver, CO, USA. ACM, New York, NY, USA, 7 pages. <https://doi.org/10.1145/3663547.3749829>

1 Introduction

Accessibility research aims to reduce barriers and enhance technological participation for people with disabilities [28, 39]. Traditionally, this work has prioritized universal, scalable solutions, tools designed to work “for everyone” by minimizing complexity and maximizing efficiency [47, 49]. While this approach has enabled progress in many domains, it often overlooks the rich diversity of disability experiences and the *situated, affective, and personal dimensions* of accessibility needs [18, 44].

Prior work in accessible technology has successfully developed numerous assistive tools, including alternative input devices [24, 29], immersive simulations [16], and bias-awareness interventions [7, 9]. However, much of this work is framed through an outsider perspective: non-disabled designers building for a generalized conception of the disabled user [19, 59]. Although participatory design and co-design have gained traction, they still often relegate disabled individuals to the role of *user* or *tester*, rather than recognizing them as *expert designers* or *knowledge producers* [3, 13]. Similarly, experience reports in accessibility remain rare and are typically written from the perspective of caregivers, clinicians, or educators [31, 51]. What is notably missing from this body of work are reflections from disabled researchers who are both the subject and the designer of their work: those who design from within disability, not merely for it. Without these voices, accessibility interventions risk perpetuating normative assumptions about what disabled people need, want, or should experience. There is an urgent need to center the personal and political dimensions of accessible design, acknowledging that design is never neutral and that lived experience generates insights that external observation alone cannot provide.

This paper presents an experience report on three research projects led by Taheri, the first author, a disabled researcher with Spinal Muscular Atrophy (SMA), a condition that results in significant motor impairment. These include: (1) *MouseClicker* [53], a facial-expression-based, hands-free input method with vibrotactile



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ACM ISBN 979-8-4007-0676-9/25/10

<https://doi.org/10.1145/3663547.3749829>

confirmation; (2) *Virtual Steps*[52], a VR-based walking simulation developed for a lifelong wheelchair user; and (3) a *Simulated Conversations* a bias intervention study with LLM-driven agents to assess people’s ability on recognizing ableist microaggressions. These projects reflect different aspects of accessibility design, control, sensation, and social dynamics, but share a common thread: reclaiming agency through design. They also highlight emotional labor, the pushback from the research community, and tensions between technical goals and lived realities.

Through analytic autoethnography, this paper contributes a reflexive account of disability-centered design that can inform more inclusive methodologies and support broader recognition of emotional and embodied labor as valid knowledge. This paper makes the following contributions:

- Documents three accessibility research projects led by Taheri, a disabled researcher, each rooted in personal need and extended through critical reflection;
- Identifies cross-cutting themes in disability-centered design, including agency, emotional labor, researcher positionality, and the risks of normative assumptions;
- Provides an autoethnographic account that illustrates the epistemic value of embodied knowledge in accessibility research;
- Argues for more inclusive and reflexive methodologies that validate lived experience as a legitimate and generative foundation for accessibility design.

By structuring this reflection through multiple projects and methodological choices, we aim to contribute to a growing discourse within HCI and accessibility that values narrative, reflexivity, and lived experience, not as anecdotal, but as deeply situated knowledge essential to the design of inclusive systems.

2 Background and Positionality

2.1 Disability Experience in Design Research

Disability has long been a focus of assistive technology, yet it is often approached from an outsider perspective that frames disabled individuals as users or patients rather than as designers or knowledge producers. In contrast, disability-led research reframes accessibility by positioning disabled individuals as epistemic agents whose embodied knowledge reshapes research design and outcomes [18, 48]. Disability-led research reframes accessibility by centering insider perspectives and embodied expertise. Autoethnography and reflective practice have proven powerful for surfacing these perspectives. Scholars such as Sengers [43], Ellis [11], and Bennett et al. [6] demonstrate how lived experience can generate insight and innovation. Crip technoscience [19] further positions disabled individuals as inventors who reshape design at both technical and epistemological levels. ASSETS experience reports have increasingly contributed to this perspective, such as Hofmann et al.’s Living Disability Theory [22], which foregrounds disabled researchers’ contributions and challenges normative assumptions in research and design. Recent autoethnographies illuminate how disabled people navigate access infrastructures, framing disability as a site of friction and creativity, and validating narrative, emotional, and sensory knowledge as legitimate contributions [25, 50, 58]. While lived experience is increasingly recognized as legitimate

knowledge in accessibility research, tensions remain in practice. McDonnell et al. [34] highlight the lack of concrete guidance for enacting disability-centered methods, and Ming et al. [35] point to how power dynamics can limit open participant feedback. These gaps underscore the ongoing need for methodological reflexivity and structural change. This paper contributes to this growing body of research by grounding its methodology in Taheri’s lived experience. Her positionality is not seen as bias, but as a central source of insight that guides and strengthens the design process. These dynamics reflect what feminist epistemologists describe as epistemic resistance—the assertion of marginalized knowledge in response to dominant frameworks—and epistemic friction, the generative tension that arises when experiential knowledge challenges disciplinary norms [27, 42].

2.2 Critiques of One-Size-Fits-All Accessibility

Mainstream accessibility efforts often strive for broad applicability and scale, favoring universal design principles and general-purpose tools [17, 56], but scholars have criticized such “one-size-fits-all” models for reinforcing narrow norms and failing to accommodate individualized requirements, as these approaches can obscure the diversity and complexity of access needs [14, 46]. Universal design, though originally inclusive in intent, has sometimes been used to marginalize personalized interventions [2, 57]. Participatory design, when tokenistic, can reproduce standard solutions rather than fostering radical alternatives [10, 33, 37]. Recent work calls for customizable, adaptive systems that reflect the variability of bodies, environments, and preferences [15, 54]. These systems recognize access as fluid and context-dependent, shaped by emotional, cultural, and interactional factors. We build on these critiques by showing how each of Taheri’s projects emerged from individual need and experience, offering design insights that extend beyond a single case.

2.3 Emotional and Embodied Knowledge in Accessibility

In many areas of computing and engineering, objectivity and generalizability are often prioritized [4, 38]. But in disability-centered design, personal experience, emotion, and embodiment are not only relevant but essential [32, 45]. These elements, grounded in everyday negotiations of access, acted as both constraints and catalysts in our design practice. Feminist HCI and somaesthetic design emphasize bodily sensation, discomfort, and affect as analytical tools [4, 12, 23]. Disability studies has similarly highlighted pain, joy, fatigue, and pride as core to understanding how technologies function in practice [32, 40, 41]. Wendell’s concept of the “unhealthy disabled” foregrounds the embodied realities that technical or social solutions cannot erase [55]. Designing from lived experience demands emotional labor, revisiting marginalization and translating pain into design insight [10]. Rather than distractions, these emotions are central to the generative process.

Our work aligns with these traditions, treating emotion and embodiment as methodological assets.

2.4 Author Positionality

Atieh Taheri approached this research as a disabled woman with Spinal Muscular Atrophy (SMA), a disease that has resulted in severe motor impairment and lifelong wheelchair use. Her trajectory in HCI and accessibility research has been shaped by both intellectual curiosity and personal urgency, the need to create systems that accommodate and empower bodies like hers. This work is not undertaken from a distance. **Misha Sra**, **Patrick Carrington**, and **Jeffrey Bigham** are faculty members in HCI whose research spans accessibility, embodiment, and AI. Sra collaborated on *MouseClicker* and *Virtual Steps*, contributing to system design and methodological framing. Carrington and Bigham supported the *Simulated Conversations* study, offering critical feedback on study framing, ethics, and LLM integration. All co-authors recognize Taheri’s experiential authority as central to this work and prioritized her interpretations when lived experience conflicted with external perspectives. This collaboration model ensured rigor while preserving the emotional and epistemic integrity of experience-driven design.

3 Methodology: Analytic Autoethnography

We drew upon autoethnographic methods [8, 11, 21], which position the researcher’s personal experience as a legitimate and primary generative source of data. We adopt Anderson’s five-criterion analytic autoethnography [1], positioning the first author as *complete-member researcher*. We did not maintain formal fieldnotes or journals. Instead, our analysis was grounded in a constellation of experiential data: (i) vivid recollections of key design moments, emotional responses, and interactions with users and systems, (ii) informal notes in Google Docs, emails, and prototype records that captured evolving decisions and reactions, and (iii) iterative conversations among co-authors. While memory is inherently subjective, in this context, it served as a valuable site of design insight. The emotional salience and repeated revisiting of key moments – through meetings, presentations, and documentation – helped reinforce their coherence and relevance over time. Themes discussed in Section 5 emerged through iterative reflection: revisiting prototypes, re-reading correspondence, memoing, and collaborative discussion. Consistent with analytic autoethnography, our goal was to treat situated experience not as anecdote but as a legitimate site of design insight and methodological contribution.

4 Reflections on Three Disability-Centered Design Projects

4.1 Project 1: MouseClicker – Reclaiming Control

MouseClicker [53] began with a deeply personal challenge: clicking a mouse, a trivial gesture for many, posed a barrier to computing for Taheri due to limited hand mobility. While many assistive systems offer cursor control, few replicate the immediacy and sensory affirmation of a physical click. This gap was not just technical: it undermined the embodied digital agency. To address it, a hands-free input system was developed that uses facial expressions to trigger mouse clicks, combined with vibrotactile feedback. Although technically simple, it revealed deeper design questions. Visual cues alone proved insufficient—tactile confirmation was essential to building

trust and intentionality. As Taheri described, “When I first felt the vibration, I experienced something rare: a sense of control that was not abstract or delayed but immediate and embodied.” The system was evaluated through personal use and a broader haptic perception study involving non-disabled participants, but its most significant insights emerged from Taheri’s reflections. She emphasized the importance of the vibrotactile confirmation in reinforcing intentionality, making the experience not only functional but emotionally resonant – a rare combination in current assistive technologies (ATs). During the review of this work, one reviewer posed a series of questions that surfaced a core tension in accessibility design:

“Is there any value in such a mechanism versus a simple visual display? [...] It seems unnecessarily complicated. [...] Is replicating the haptic experience of using a mouse even appropriate?”

These questions reflected a functionalist perspective, an approach in accessibility and HCI design that emphasizes simplicity, efficiency, and task completion, often at the expense of sensory, emotional, or embodied dimensions of experience [20]. Within this paradigm, vibrotactile feedback was an indulgent addition, superfluous at best, and misguided at worst. But for Taheri, it served not as an optional enhancement but “it was the bridge between intention and action.” That bridge was not merely functional, but emotional, embodied, and deeply personal. This reviewer feedback highlighted a core tension in accessibility research: the gap between *technical sufficiency* and *experiential adequacy*. A visual cue might signal that a click occurred, but for someone who cannot feel that click through their own body, the absence of tactile feedback meant the absence of certainty, trust, and agency. As Taheri reflects, “*MouseClicker* taught me that accessibility is not only about whether a task can be completed, but about how it feels to complete it—and whether that experience affirms or diminishes one’s sense of control.”

MouseClicker exposed the limitations of evaluating ATs solely based on task completion metrics. Accessibility is not only about whether an action can be performed, but about how that action is experienced. In this case, tactile feedback enabled a more immediate, embodied sense of control that could not be replicated through visual feedback alone. This project also challenged dominant HCI norms around simplicity, minimalism, and efficiency, values that often shape mainstream design standards. *MouseClicker* emphasized that designing for access requires attention not just to performance but to presence – to how it feels to act, to control, and to be in the loop. “*MouseClicker* remains one of the most personally meaningful systems we have built,” Taheri remarked, “precisely because it was born out of frustration, refined through my own embodied experience, and defended against the assumption that emotion is extraneous to function.”

4.2 Project 2: Virtual Steps – Walking Through Assumptions

Virtual Steps [52] was born from a personal and atypical question: *What would it feel like to walk, as someone who never has?* Rather than focus on performance metrics, this project began with a desire to explore the emotional and embodied dimensions of movement in VR. A slow first-person simulation offered Taheri, a space for

imaginative, affective exploration. For Taheri, the act of walking in VR was neither simply empowering nor unsettling; it was layered. It surfaced complex emotions: curiosity, estrangement, and a reconfiguration of bodily identity. “It challenged my own sense of self,” she noted. But the community’s responses were equally telling. Many expressed genuine interest and appreciation, while also acknowledging their initial discomfort with the idea of simulating walking. Some shared that they had assumed such experiences might conflict with the social model of disability, which emphasizes adapting environments rather than encouraging disabled people to approximate non-disabled norms. Even well-meaning concerns revealed latent discomfort with disabled users desiring experiences perceived as non-disabled. Others admitted that they had questioned whether replicating walking was appropriate at all – concerned that it might inadvertently reinforce normative ideals.

What emerged from these reflections was not opposition, but an unexamined assumption of consensus, a belief about what disabled people do or do not want from technology. In trying to avoid ableist implications, these reactions unintentionally surfaced a recurring issue in accessibility work: speaking on behalf of disabled users, rather than centering their perspectives. The assumption that certain desires, such as the wish to walk in VR, are inherently inappropriate, even when voiced by disabled people themselves, reveals how rigid interpretations of advocacy frameworks can inadvertently limit agency and imagination. This reveals a deeper tension in accessibility research: While the social model remains foundational, it can sometimes be invoked in ways that unintentionally constrain disabled agency, curiosity, and imagination. The idea that simulating walking might be inherently inappropriate for wheelchair users, though well intentioned, reflects an overcorrection, one that may prioritize ideological consistency over personal complexity. Accessibility must do more than remove barriers; it must also make room for exploration, ambiguity, and individual desire, even when those desires fall outside familiar frameworks. *Virtual Steps* made it clear that walking in VR can be meaningful, even when that meaning is complex or unresolved. It also demonstrated how some of the most critical work in accessibility involves questioning not only technical limitations but also the cultural assumptions that shape what is considered valid or worth pursuing. Designing from lived experience requires space for emotional nuance and a willingness to move beyond assumed consensus about what a community does or does not want.

4.3 Project 3: Simulated Conversations – Surfacing Bias Through Dialogue

This project emerged from a different kind of need: not for control or imagination, but for recognition. In academic, clinical, and everyday environments, Taheri had encountered countless moments in which ableist assumptions – subtle slights, awkward compliments, or patronizing questions – often left unacknowledged or dismissed as benign. This project asked: *Can we help people recognize these behaviors by placing them in simulated social situations?*

Simulated Conversations was designed to explore this question through an interactive LLM-driven platform. Participants engaged with a fictional disabled character, while a conversational coach,

also driven by an LLM, offered either neutral or subtly ableist guidance. By completing pre- and post-test surveys, participants’ perceptions of the emotional tone and social appropriateness of the interactions were evaluated. Unlike the other projects described in this report, this work is still ongoing. We include it here because the design process itself has surfaced both technical and ethical challenges. Technically, generating coherent, emotionally responsive conversations while maintaining believability and contextual relevance using LLMs required extensive prompt engineering. Achieving nuanced yet controlled responses was challenging, especially given the LLM’s optimization to avoid harm. Balancing realism with experimental control was particularly challenging, given the sensitivity of the scenarios and the unpredictability of LLM outputs.

What distinguished this project was the embedded emotional labor. The scenarios in the pre- and post-study surveys were based on the lived experiences of Taheri and her peers. Writing them meant revisiting condescension and discomfort to recreate the affective texture of those interactions.

There were concerns about desensitizing participants or trivializing harm, but the project operated on the belief that discomfort can be productive. This work aimed to demonstrate that bias lives in interaction, not just ideology. Shifting interactions requires practice and emotional engagement, not just guidelines. Even incomplete, *Simulated Conversations* revealed that social accessibility is inseparable from affective labor and that AI-based accessibility research must negotiate authenticity, ethics, and emotional sustainability. The project illuminated the complexity of tools that ask participants to confront bias relationally rather than abstractly. It revealed that the burden of exposing bias often falls on those most affected, but when approached with care, such tools can open necessary conversations.

5 Cross-Cutting Themes and Discussion

Across the three projects, several themes emerged that extend beyond the results of the individual project. These themes highlight how designing from lived experience challenges dominant assumptions in accessibility research.

Reclaiming Agency Through Design. Each project originated from a personal constraint or curiosity, but evolved into a form of reclaiming agency. *MouseClicker* restored a basic but essential form of interaction often taken for granted. *Virtual Steps* opened the possibility of imagining a bodily experience Taheri had never had, while *Simulated Conversations* created a space where others could confront the subtle harms of ableist microaggressions. These projects were not just about solving problems; they were about redefining/expanding what disabled people are allowed to do, feel, and imagine.

Emotional Labor as Design Practice. Emotional labor was not incidental but central to each design process. Revisiting exclusion, confronting internalized ableism, and translating personal histories into interventions required vulnerability. In each case, this labor contributed directly to the insight and innovation achieved. While often unacknowledged in HCI frameworks [5, 30], emotional labor here was integral to the design methodology.

Tension Between Insider Knowledge and Research Norms. Throughout the process, moments of friction emerged between

the insider knowledge of Taheri as a researcher and the dominant disciplinary expectations. Some reviewers saw vibrotactile feedback as unnecessarily complicated; others hesitated at the idea of simulating walking. Using LLMs to explore bias triggered anxieties about emotional risk. These moments of discomfort represent recurring epistemic friction sites: conflicts between embodied, affective knowledge, and disciplinary norms that prioritize generalizability, simplicity, or abstraction. In choosing to center lived experience, we engaged in epistemic resistance: asserting the legitimacy of knowledge that is often treated as too specific, too emotional, or too inconvenient to fit within conventional research paradigms.

The Fragility of Inclusion. A final theme is the fragility and contingency of inclusion itself. Inclusion is often framed as a destination achieved through design guidelines [26, 36]. However, these projects demonstrate that inclusion is not a stable outcome, but a contested, iterative process shaped by discomfort, negotiation, and critical reflection. There is no formula for “inclusive design” that bypasses discomfort or contradiction. Instead, accessibility must be approached as a continuous and reflective practice, one that requires ongoing reexamination of assumptions and values, and is grounded in situated experience.

6 Implications for Accessibility Research

6.1 Validate Lived Experience as Rigorous Knowledge

Accessibility research must move beyond viewing lived experience as anecdotal or secondary. When disabled researchers design from within their own realities, they generate forms of situated knowledge that are critical to understanding access as an emotional, cultural, and identity-based phenomenon. These contributions should be acknowledged as legitimate forms of evidence. They are not incidental but are often only accessible through methods like autoethnography or disability-led design. Treating individual knowledge as lesser bars researchers from engaging with some of the most nuanced, embodied, and context-specific understandings of access. Recognizing lived experience as rigorous knowledge is essential for justice and epistemic completeness. Excluding it erases deeply situated understandings of access.

6.2 Expand the Definition of Access

Traditional accessibility work often focuses on minimizing friction or enabling functionality. These are important goals that must now be expanded. Access is not only about achieving parity with non-disabled norms; it is also about engaging with the world on one’s own terms. This requires design approaches that account for affect, agency, and imagination, and that make space for ambiguity, personal meaning, and non-normative desires, not just compliance or efficiency.

6.3 Acknowledge Emotional Labor in Design

Emotional labor, including revisiting marginalization or integrating personal histories, is often rendered invisible. For disabled researchers, this labor is central to design insight. Acknowledging it requires co-design models, collaborative authorship practices,

and institutional recognition that emotional work is also epistemic work.

6.4 Interrogate Normative Frameworks

Reviewer feedback, disciplinary conventions, and institutional pressures often privilege generalizability, simplicity, and abstraction, criteria that can unintentionally exclude disabled perspectives. As shown in this report, even well-meaning responses may carry embedded assumptions about what disabled people should or should not want. Supporting work that is emotionally complex or specific is essential to avoid replicating the exclusions it aims to dismantle.

6.5 Design for Complexity, Not Closure

Rather than seeking universal solutions, accessibility research should embrace multiplicity and context. This includes designing tools that support personalization, simulations that accommodate emotional nuance, and methods that foreground lived experience. Inclusion is not a fixed endpoint, but an ongoing negotiation shaped by evolving needs, diverse embodiments, and plural understandings of access. These implications call for reframing of accessibility research not just to remove barriers, but to reimagine what design and expertise can look like when disability is fully integrated as a source of insight, creativity, and critical perspective.

7 Limitations and Future Work

These reflections are grounded in the lived experience of a single disabled researcher and, while valuable, are necessarily partial. The analytic autoethnographic approach privileges specificity and subjectivity, which may not generalize to all disabled researchers or users. Additionally, some aspects of the projects, particularly *Simulated Conversations*, are still in development. Future work will involve formalizing evaluation metrics and expanding participant samples to assess broader impacts and limitations. Further research could also explore how emotional labor manifests across a wider range of accessibility contexts and how institutions can better support the epistemic contributions of disabled researchers. Integrating these perspectives into mainstream design workflows remains a critical and ongoing challenge.

8 Conclusion

This paper has reflected on three projects, *MouseClicker*, *Virtual Steps*, and *Simulated Conversations*, each rooted in the lived experience of Taheri, shaped by emotional labor, epistemic friction, and disciplinary tension. These projects moved beyond functional goals, engaging deeply with questions of agency, affect, and social recognition. We argue that designing through disability is not simply a perspective – it is a critical methodology that challenges dominant norms in accessibility. It centers embodied experience as a resource, not a limitation, and reimagines inclusion as a dynamic process of negotiation, reflection, and care. While the HCI accessibility community has begun to recognize lived experience as legitimate knowledge – as evidenced by an emerging body of disability-centered autoethnographies – we argue for a shift in how this knowledge is engaged. Lived experience must be structurally supported in reviewing practices, funding models, and how rigor

is defined. We call on the community to invest not just in publishing experiential insights, but in redistributing epistemic authority, ensuring disabled researchers shape the questions, standards, and futures of accessibility research.

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