
Disabled and Design Researcher: An Unexpected Relationship?

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Abstract

This paper aims to start a conversation about rethinking design research environments and practices, as socially and physically accessible and engaging for design researchers with mixed abilities. We report a first-person account of how a design researcher can face physical and social exclusion in related environments. We recall several instances from a disabled design researcher's experiences in a design lab, in a design conference, and in the design research process itself. We recommend ways to transition design labs and research practices to more inclusive infrastructures and practices.

Author Keywords

disability; inclusive environments; inclusive design research; design lab; first person experience; disability identity

CCS Concepts

•Social and professional topics → People with disabilities;

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Figure 1: In this photo, I am giving a presentation in the focus group room using both my laptop and 1/2 of the whiteboards



Figure 2: In this photo, I am presenting my paper at DIS 2019 on a stool.

Related Work

Design labs are environments with special equipment and tools intended for designing products, systems, services, experiences, or interactions by conducting interdisciplinary research concerning social life [1]. Previous work in HCI shows how design-related practices and environments can marginalize communities according to gender [13, 15], age [7, 10], and socioeconomic groups [26]. At the same time, the positive relationship between disability and the maker movement that leads to democratization and empowerment is evident [17]. More accessible practices of Maker spaces and design workshops [16, 4] lead to empowerment through making [16]. Such cooperation can also contribute to autonomy, well-being, and positive aging for older residents [7]. Still, aspects of practicing making such as instructions, supplies, and cultures are known to be inaccessible for people with disabilities [2, 18, 24].

From a long term engagement point, disabled researchers face long term challenges as academics in their work (below is a summary of key points from [21]): These challenges can include discrimination related to hiring and work conditions [8, 11, 9, 22, 12], physical accessibility issues (Inaccessibility of conferences [11], lack of interpreters for impromptu meetings [22], inaccessibility of campus services [11] and academic articles and books not being available in accessible formats [11]), and social aspects (Difficulties integrating into the culture and politics of their campuses [22], exclusion from social events and faculty meetings [8]). Some of the above-mentioned challenges would also apply to the challenges associated with being a disabled design researcher working in design labs.

The challenges of being a disabled design researchers include the challenges associated with being a disabled researcher. The literature on disability studies (DS) focuses on disabled researcher working with disabled people as participants [5, 27] or non-disabled researcher working with

people with disabilities [25] and the concept of being an insider. The current status quo on accessibility and disability research in HCI related fields -in parallel to DS- highlights the necessity of involving disabled people in full [14] [23], rethinking the categories of “designer” and “disabled” [3] and the disabled identity in relation to HCI research [28, 6, 20].

In this work, we report a first-person account on how disability is physically and socially lived in design research related environments. We list the daily experiences in a design lab, challenges faced while conducting a research study, and the experience of a rare and repetitive event, namely the experience of visiting an international design conference. We illustrate classical duties, and introduce related environments and actors. Our aim is to detect possible action points for building a more inclusive design research environment in terms of infrastructural, social and cultural aspects. From here on, until the discussion section, we use the first-person singular “I” to emphasize the importance of the first author’s lived experiences. All captions and sidebars are also written in first person singular.

The Lived Experience of a Design Researcher with a Disability

I am a design researcher with a research focus on accessibility. I am a person with a visible disability (110 cm tall, with an unusual spine structure due to a myopathy). I self-define as a disabled and take pride in my disability”, but my condition does not always disable me. Still, on some occasions (standing for a long time, walking for long distances, and being faced with items placed too high), the environment can disable me.

A Full-time Member in a Design Lab

The design lab environment is -for me- almost always

Design Lab Environment:

The interdisciplinary design-lab where I work is an open office environment. The physical infrastructure is a focus group room, a maker's corner, a kitchen. It has standard office facilities like a printer, socializing materials, and a maker's corner. In the design lab, each Ph.D. student attends to independent research, research for existing projects (RA), and has teaching duties as an assistant (TA).

physically accessible (no significant obstacles, a central desk, and the possibility to ask for help, if needed). Still, I encounter some accessibility problems. Usually, I fix them alone through appropriating different objects. From day one at work, I started developing personal solutions to make and keep those things -that I frequently use- accessible. For example, the printer was too high to reach or the kitchen in the lab was somehow inaccessible. I made my accommodation needs visible to people in the lab (e.g., I told others that I use that little box as a step and asked that they please not remove it or I informed others that I use the kitchen less frequently (and created notes on what I need to reserve in the kitchen). Over time, I started using more accessible facilities more frequently (e.g. the focus group room has whiteboards -starting low- that are practical, so I use the room frequently, see Figure 1). The making corner however, is still not fully accessible for me (tables are too high, equipment wall is too far away to reach), but I did not take any action, as I do not need them. Since I joined the lab 2.5 years ago, I have already learned various new digital skills. But I never considered gaining maker skills, as this could be too much of a burden for everyone else.

Distribution of Duties and Social Life

The workload of TA and RA duties is decided with a non-hierarchical discussion among group members. I do not think that I have specific duties given to me related to my identity as a disabled person. I sometimes need to take action to sustain accessibility (e.g. in one of the classes I teach, I prioritized the location of the class based on the accessibility. Similar cases occur from time to time, where the group decides together based on the feasibility of the accessibility request (mostly accessibility is prioritized, sometimes a social solution is developed to accommodate both sides (e.g. if a specific room with equipment is needed but not accessible, someone assists me). On the social part, how the social events at the lab are accessible to me relates with the nature of activities that are being planned. Activities away from home, such as ski or such as ski or camping trips, are hard for me to relate

relate and connect to, as those are not among the activities I have previously engaged with, and they need closer attention. Even if I most probably can survive all of them, I am less likely to attend to such activities. When I plan for such activities, the possible consequences of being away are too stressful for me, and I would prefer not to share those with colleagues. If majority of the events are around this line, it is possible that I will become socially disconnected.

Being a Design Researcher with Disabilities

My appearance and my research topic sometimes intersect with each other unintentionally. A recent study I conducted was about accessibility-related processes on a university campus. I designed the study (sampling, interview structure) and conducted the interviews (with disabled and non-disabled participants). Throughout the interviews, there were several instances where participants formed their answers around me as a "disabled student". More than once, I found myself being interrupted as a researcher. Upon discussion with my supervisor, we decided to put this openly to the research paper. We included a statement for disclosing my identity as a disabled person. This was not without a feeling of discomfort. Later, the reviewer of our submission suggested that the interviewees were possibly unable to separate their answers about the accessibility issue from me, a researcher with a visible disability. The reviewer specifically mentioned that this does not have to mean that the researcher with a disability should not be the one conducting the interviews. However, that question is impossible for me to answer in full. So, in the discussion, I am asking several provocative questions to open this concern to speculation.

**Interactions with International Community:
Presenting My First Full Paper:**

I attended to DIS 2019 to present my first full paper. During the application, I was satisfied with the very detailed

questions about possible accommodation needs. In the following process, accessibility chairs contacted me, and we arranged the accommodations together. Since traveling this far is already full of accessibility challenges, I traveled with my sister. My family covered the travel of my sister. For my presentation, I needed a ramp to the stage and a stool to reach the stand while presenting the paper (see Figure 2). I ended up presenting on a somehow moving stool, which was almost 2/3 of my height. This corresponds to an average person (1.65cm), presenting on an unstable object of 110cm. The attendance at the social events was again the burden. The buffets needed extra care, as the food was placed too high. The cocktail tables and the need to stand for long times excluded me from the cocktail time. I had my sister to assist me, but still spending time in that area was not comfortable (the dinner and the cocktail were essential parts of the event for the many).

Discussion: Sustaining a Non-Toxic Disabled Design Researcher Life

This paper aims to provoke all the design lab members to rethink their spaces, research and socialization practices. The provocative questions we list are a step towards building more constructive and inclusive design environments.

Basic Infrastructural Engagements:

Considering both the experiences in working in a Design Lab and attending DIS conference, the very first insight to share is a need for systemic improvements for inclusive basic infrastructures. It is visible in both two instances that infrastructural aspects are genuinely in connection with social aspects.

Personal Accommodations and a Secure Social Network:

One lesson we learned from the processes of making the Design Lab and the visit to DIS accessible for one individual with one disability is the importance of being socially comfortable. Many occasions require personal accommodations, and social events are not exceptions.

Topic Choice and Rights as Design Researcher:

Even though the researcher thinks that their practice as a researcher is something independent from their identity, “not to disclose” the disabled identity seems not to be an option.

Provocative Questions

Is the design lab I work considered accessible (physically) or inaccessible (socially)? Could I be more interested in making and design-led work, if the maker corner was accessible? (see [28] on an example of collaborations of disabled and non-disabled researchers in a research lab environment, and on how non-disabled peers might perceive disabled researchers). At DIS2019, could I socialize with others, if they organized the conference socialization differently? (See [19] on a disabled researcher’s experiences on attending remotely to a conference using telepresence robots). How can I separate my identity as a disabled person from my researcher identity, since “disabled” becomes externally assigned identity from my participants? (See [6], a disabled researcher seen within the researcher identity; see [3] on rethinking categories of “disabled”, “designer”, “user” and “designer”). How can I set the borders for my participants so that they can separate those? (See [6] on how the process, participants and researchers are shaping each other, and how their identities are shaping and shaped through the research, and the opportunities such interactions bring). When is it necessary for me to disclose my identity, given that it is not something that disables me in my work? (See suggestions in [6] on four stand points to systematically reflect on identity in participatory design process). How should I approach my research data, considering that they might be biased because of me? (See [6], on rethinking about construction of researcher identity while engaging on research and how this might influence the research data, in line with the standpoint theory, stating that identity of the researcher may shape the research conducted; see [20] on research by disabled researchers considered as not producing appropriate kinds of knowledge.

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