Understanding the Role of Socio-Technical Infrastructures on the Organization of Access for the Mixed-Ability Collaborators

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ABSTRACT

Positioning disabled people as deficient, dysfunctional, and locating the 'problem' of disability within the individual, the overmedicalized, individualistic, and not equity-oriented perspectives of disability have led to oppression, discrimination, and exclusion of disabled people from important parts of public life. The global politics of disability rights and disability movements have brought thorny questions regarding the nature of dominant explanations. Equity-oriented perspectives and collaborative approaches regarding organization and distribution of access started to gain visibility. HCI research has a vital potential to contribute to this by providing related tools and technologies for integrating equal access in the collaborative organization of access. Considering the existing literature, the question of how access is collaboratively organized, negotiated, distributed and scaled through socio-technical mechanisms especially at an institutional level, as well as how mixed-ability groups reorganize access by interacting with institutional socio-technical structures remains open. In this research, I aim to extend the body of literature in collaborative access by presenting the importance of socio-technical perspectives for designing collaborative technologies to support equal distribution of access. My research is about the significance of equity perspectives in access and interaction. Specifically, this research focuses on understanding the role of socio-technical infrastructures for the organization and distribution of access by mixed-ability collaborators and developing design insights for socio-technical mechanisms to support equal distribution of access for people with disabilities.

CCS CONCEPTS

• **Computer systems organization** → **Embedded systems**; *Redundancy*; Robotics; • **Networks** → Network reliability.

KEYWORDS

accessibility, access work, collaboration, negotiation of access, distribution of access, gatekeeping, socio-technical perspectives, people with disabilities



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1 INTRODUCTION

My research is about the significance of equity perspectives in access and interaction. Specifically, this research focuses on understanding the role of socio-technical infrastructures for the organization and distribution of access by mixed-ability collaborators and developing design insights for socio-technical mechanisms to support equal distribution of access for people with disabilities.

Positioning disabled people as deficient, dysfunctional and locating the 'problem' of disability within the individual, the overmedicalized and individualistic perspectives of disability have led to oppression, discrimination and exclusion of disabled people from the important parts of public life [27]. The global politics of disability rights and disability movements have brought thorny questions regarding the nature of dominant explanations. Equity-oriented perspectives and collaborative approaches regarding organization and distribution of access started to gain visibility. HCI research has a vital potential to contribute to this by providing related tools and technologies for integrating equal access in the collaborative organization of access.

The fields of CSCW (Computer Supported Collaborative Work) and HCI (Human Computer Interaction) have been increasingly exploring the importance of accessible technologies for equity and inclusion. More specifically, there is growing research on how technologies for collaborative interactions could shape equal access for the members of marginalized communities, with emerging interest in people with disabilities [10, 13, 19, 21, 24, 32, 34]. Overall, this previous work shows how equity oriented design of socio-technical systems and related tools might support negotiation and equal distribution of access for marginalized communities through supporting social interactions, information sharing and community building, visibility and activism. My positioning in my research in the context of accessibility is in alignment with these works, in terms of putting equity in center and looking into socio-technical designs to ensure equal access.

Among diverse sub-fields of accessibility work in HCI and CSCW, my work also closely relates to the collaborative negotiation of access from the scholars in HCI working on social and collaborative accessibility [2, 5, 6, 19]. Collaboration and mutual effort of mixed-ability people have been crucial for creating and sustaining

accessible environments. Previous work looked into the situational and collaborative nature of disability and accessible experience which are dynamic and includes people with different abilities (mixed-abilities) [5, 6, 19]. Through these interactions, previous work showed the importance of collaboration in applying creative strategies to increase access in mixed-ability groups at the context of home [5]. and work [6, 19]. This body of work focuses on equal distribution of access around the interactions between small mixed-ability dyads, pointing to the value of mutual labor, the importance of work distribution, independence as well as inter-dependency [2].

However, the question of how access is collaboratively organized, negotiated, distributed and scaled through socio-technical mechanisms especially at an institutional level, as well as how mixed-ability groups reorganize access by interacting with institutional socio-technical structures remains open. In this research, I aim to extend the body of literature in collaborative access by presenting the importance of socio-technical perspectives for designing collaborative technologies to support equal distribution of access. With this aim, my Ph.D work for the cumulative thesis until now consists of 1 full article (DIS'2019) on online interactions around disability, 1 LBW (DIS'2020) on access and design research, one full article on distribution of access on a higher education institution (under revision, CSCW'2022), and one ongoing project on organization of access through collaborative communication technologies by a mixed-ability expert group with the aim of cross-disability solidarity (planned to be submitted to CHI'23). Within that scope, I asked the following overarching research question and sub-research questions that guided my research process and presented the related deliverables:

(Main-Q) "How do socio-technical infrastructures that mixed-ability collaborators interact within shape the negotiation and distribution of equal-access for people with disabilities?"

I conduct a set of different case studies in the area of autism parents, higher education, mixed ability activist communities.

My research covers different contexts such as online media and higher education with the aim of understanding the role of socio-technical infrastructures on the organization of access for the mixed ability groups, while looking into different interaction types (bottom-up vs. institutional, physical vs. online). Since my focus is to understand and uncover the power-relations between relatively larger mixed-ability groups that organize access and try to understand how design may challenge this to ensure equal-access, I aim to choose contexts that reveal different power relations (unequal power distribution vs. equal power distribution) within different socio-technical structures. This aim led me to focus on different contexts (online groups, higher education settings, social enterprises) through my research. Even though this may seem like the scope of my research is a bit broad for a PhD thesis, all the cases are selected carefully to reveal insights about different power relations and different socio-technical structures, around the main research question. All the cases help me to have an overarching and inclusive understanding of the role of socio-technical infrastructures on the organization of access. I provide more information on this in the following sections when I share the work packages.

In the following parts, I introduce the research background, methodology and completed, ongoing and planned case studies.

2 BACKGROUND

In line with the questions, this research brings together literature to illustrate the rationale behind examining how access is organized, from the perspective of Social Model of Disability and Social Justice Oriented Interaction Design. Further, this section discusses the role of socio-technical structures on an organizational level by presenting studies of collaborative technologies around access and collaborative organization of access by mixed-ability groups in different contexts.

2.1 Why looking at how access is organized is important?

Through my research, I use the lens of the Social Model of Disability together with Social Justice Oriented Interaction Design. The way a disabled individual is positioned within a system can easily restrict their access to multiple resources. Positioning disabled people as deficient, dysfunctional and locating the 'problem' of disability within the individual, the over-medicalized and individualistic perspectives of disability have led to oppression, discrimination and exclusion of disabled people from the important parts of public life [51]. The global politics of disability rights and disability movements have brought thorny questions regarding the nature of dominant medical explanations. The social model of disability defines and positions disability as a social state rather than a medical condition, focusing on the environmental and social barriers [22]. The social model suggests that the society is responsible for the full participation of all people and needs to evolve to be more inclusive [4, 8, 15, 22] and collective action is likely to be required to challenge the existing systems [9]. There is a growing literature within HCI and CSCW that positions their research, which is inspired by the premises of the social model, as contributing to the social model of disability [18, 20, 25, 26, 28, 30, 31, 33]. Also, equity and social justice oriented perspectives [1, 14, 16, 23] and collaborative approaches regarding organization and distribution of access [5] started to gain visibility and HCI research has a vital potential to contribute to this by providing socio-technical perspectives for collaborative negotiation of access, at the institutional and systemic levels. Therefore, while exploring the organization and distribution of access, I turn my attention to institutional level socio-technical systems.

I use social justice perspective as a lens to understand the organization of access, and search for ways to support this organization process to ensure equal access for people with disabilities. While engaging with socio-technical systems in the area of access, Social Justice Oriented Interaction Design scholarship in HCI expanded my view. Social Justice Oriented Interaction Design developed for research that works around systemic or wicked problems that present challenges regarding their complex and political nature and scope [14]. I position my research as being wicked and complex. It is in relation to social and political aspects of access. Also it deals with design of larger socio-technical systems at the institutional level and for large groups of collaborators. Social Justice Oriented Interaction Design offers strategies that include designing for transformation, recognition, reciprocity, enablement, distribution, and accountability [14]. Rather than providing specific actions or methods, these strategies provide trackable ways to engage with social issues [14]. My research specifically relates to and follows the transformation,

reciprocity and distribution strategies of Social Justice Oriented Interaction Design orientation. First, designing for transformation draws attention to structural inequalities including ableism that include multifaceted interactions between individuals and communities. My research focuses on structural and large-scale interactions around access that produce inequalities for people with disabilities, by broadening the design space of current HCI literature on the issue. Based on social, interpersonal and institutional relations, designing for reciprocity focusing on engendering more equitable relationships [14]. Here, the arrangement of socio-technical systems that open a space for more equitable relationships between different stakeholders is presented as an example of potential change [14]. Focusing on mixed-ability collaborators, my research also aims to develop insights to support spaces that would foster more equal interactions around access. Finally, designing for distribution focuses on how socio-technical systems can be designed to support more equal distribution of resources such as power or knowledge. In line, my research tries to explore possibilities for socio-technical systems to support equal distribution of access.

2.1.1 Social Justice and Disability Justice Perspectives in HCI. There is a recent and growing interest in the HCI community to apply the fundamental concept of social justice to interaction design and technology development. Pioneering studies outline the key strategies of social justice oriented interaction design to target designing for transformation, recognition, reciprocity, enablement, distribution, and accountability [14]. In recent years researchers have identified diverse social justice issues that can be addressed by the field of HCI. In alignment with this work, my research also attempts to approach the organization of access for people with disabilities as part of HCI's move towards social justice. As the current research highlights, designing for alternative forms of justice is a very complex process, but discussing these is also necessary for the future of designing digital technologies in social, third sector, or civic contexts [14]. Further, contemporary discussions in HCI and CSCW focus on disability justice [68]. The principles of disability justice presented as, intersectionality, leadership of the most impacted, anti capitalist politics, cross movement solidarity, recognizing wholeness, sustainability, commitment to cross disability solidarity, interdependence, collective access and collective liberation [3]. In a recent CHI workshop Dreaming Disability Justice, scholars criticized existing assistive technology research in HCI which may not always attend to the complex lived experiences of disabled people [29].

2.1.2 Social Model of Disability Perspective in HCI. There is a growing literature within HCI and CSCW that positions their research that inspired by the premises of social models and contributes to the social model of disability in the context of neurodiversity and mental health [18, 25, 28, 31], including learning difficulties [18] and dyslexia [31]; aging [20] and physical disabilities [26, 30] including visual impairments [30], mobility impairments [26] as well as SIIDs [33]. This growing body of work has mostly focused on how the social model of disability informs the design of assistive [20, 25, 33] and interactive technologies [26, 28] or the design process [18].

This growing body of research in HCI helped me to construct my view on access while working around technology and access. As I explain these more in the following subsections, my work also revealed similar perspectives with these studies of the social model of disability. However, even though HCI work used social model to inspire design process in general or the design of assistive and interactive technologies, studies of collaborative negotiation of access or socio-technical level studies of access lacked social model driven perspectives. By looking at institutional level organization of access to inspire collaborative technologies within socio-technical systems where the mixed-ability collaborators operate, I believe that the Social Model of Disability has a potential to inspire collaborative technologies around access as well as mixed-ability studies based on its premises.

2.2 Role of Socio-Technical Structures for Equal Distribution of Access for People with Disabilities

Trying to understand the roles of socio-technical infrastructures around organization and distribution of access, this research turns into existing research around collaborative technologies on distribution of access for diverse marginalized communities, with a focus on people with disabilities.

2.2.1 Collaborative Technologies on Distribution of Access in HCI. Research on collaborative technologies and distribution of access for people with disabilities focused on access around diverse topics such as online social or work-related interactions [13, 21, 24, 34], sharing accessibility-related experiences [32] or flexibility in disclosing disabilities through online interactions [24, 34]. For example, Zyskowski et al. showed that collaborative platforms to support participation of people with disabilities in crowd work could improve the experiences of finding tasks by matching them with required abilities such as the ability to hear audio [34]. Even further, employers can label tasks, stating the required abilities for a task [34]. Beyond just finding jobs, Ding et al. highlights the social relationships developed through online crowdwork communities and suggested a hybrid mix of crowdsourcing and online communities that combines supervising and training, as well as socializing and community building activities for platforms that include multiple stakeholders around crowd work [13]. Further, giving the flexibility to build the worker profiles, Zyskowski et al. recommended that work platforms should allow people to optionally identify their disabilities [34]. Similarly, focusing on disability disclosure around online dating communities, Porter et al. suggested using informing filtering systems such as questions or some ambiguous options like "Ask Me" rather than requiring marginalized groups to disclose disabilities [24].

In the case of social interactions among people with disabilities through online communities, Liu et al. coined the term "communally mediated integration" which stands for how people with disabilities gained confidence through providing support to each other such as organizing activities or creating employment opportunities [21]. Another study focusing on online interactions among people with disabilities, sharing lived experiences and information around using assistive technology suggested adopting a story-based approach [32]. In that, community members can share their journey around assistive technologies when providing and requesting advice, enabling community members to identify how relatable

their experience is to their own circumstances. Further, researchers stated that such platforms might benefit from enriched profiles and contributions that allow multiple forms of content creation such as sketches, photos and videos [32]. Finally, on supporting independence in care networks supported by collaborative technologies that include multiple stakeholders around care, researchers highlighted the importance of centralizing the person with the health condition in the system to support their agency and independence [10].

Overall, the studies introduced above put equity and equal distribution of access into the center and show how voices of people with disabilities are heard or silenced, how their experiences are shaped and can be better supported by designing collaborative socio-technical systems that support equal distribution of access. In the context of accessibility, my positioning in my research aligns with these works, in terms of putting equity in the center and looking into the roles of socio-technical designs and collaborative technologies to ensure equal access.

2.2.2 Collaborative Organization of Access in HCI. My research closely relates to the emerging definitions of access and disabilities from the scholars working on social and situational accessibility [33], collaborative access [5, 12] and inter-dependency [2]. Both the field of disability studies and HCI has looked into the situational and collaborative nature of disability and accessible experience which are dynamic and includes people with different abilities [5, 17, 33]. Branham et al. highlight the accessibility processes as not static, changing over time and continually being negotiated by people who share the same space [6]. In another work, Thieme et al. consider disability as *"something that is not fixed or manifested alone through the body but created through a person's social and material interactions with the world"* [30]. Similarly, according to Bennett et al., access is something that changes over time rather than being static and it needs to "continually renegotiated" based on social norms through social interactions [2].

2.3 Originality and Research Aims

Covering different contexts (e.g. home, workspace), existing research illustrates how access is collaboratively organized by mixed-ability groups, illustrated how concepts such as invisible work eventuate itself within these interactions and how socio-technical infrastructure and collaborative technologies support these interactions. However, the question of how access is collaboratively organized, negotiated and scaled at an institutional level that includes interactions of larger groups of people remains open. The collaborative accessibility work with trusted persons (e.g. co-workers and partners) is inspirational for the question of how institutional level access that includes collaborations of usually unknown others, can benefit from collaborative negotiation of access and enhancement of collaborative technologies. My work aims to extend the body of literature in collaborative access by presenting the existing challenges regarding negotiation, organization and equal distribution of access through technologies to illustrate the importance of institutional and socio-technical perspectives for designing collaborative technologies for equal distribution of access. Further, it aims to explore how experiences of people with disabilities are silenced in the processes of organization of access and how organization of access experienced and re-organized by people with disabilities. Finally, it contributes to the existing research by developing design insights for developing collaborative socio-technical mechanisms to show how collaborative technologies might support the involvement of people with disabilities into the processes of institutional level organization of access and support organization and equal distribution of access for the mixed-ability collaborators at the organizational levels.

Aligned with the research questions, my research has the following aims:

- understanding and presenting the existing challenges regarding negotiation, organization and equal distribution of access through technologies through the following cases: -for the online support seeking around access and disability by the mixed-ability caregivers,
  -for the mixed-ability collaborators, scaled at the institutional and organizational levels in the context of higher education,
- understanding how organization of access experienced and re-organized by people with disabilities through the following cases:
  -in the context of higher education institution
  -in design research spaces
- develop design insights for developing collaborative socio-technical mechanisms to:
  -support alternative, bottom up and shared definitions and experiences around access to emerge
  -support organization and equal distribution of access for the mixed-ability collaborators at the institutional and organizational levels,
  -support the involvement and participation of people with disabilities into processes of organization and distribution of access through collective action and activism.

3 METHODOLOGY

Below, I provide an overview of the methodology that I follow through my research process. Further, I present my research stance and positionality very briefly. In the last subsection, I give a detailed description of my work packages.

3.1 Overview of the Methodology

The overarching aim of this research is to understand the role of socio-technical infrastructures for mixed-ability collaborators for the organization of access and how they shape collaborative negotiation and equal distribution of access for people with disabilities. Thus, this research follows exploratory and social constructivist research perspectives [11] and is conducted with a qualitative research approach. Social constructivist research philosophy often addresses the processes of interactions among individuals and focuses on the context they work or live to understand in order to gain more insights regarding these interactions [11]. Further, as the social constructivist approach also highlights, researchers need to recognize their own backgrounds that may shape their interpretation and these need to be acknowledged [11].

In order to answer the presented research questions and gain research expertise, I applied the following qualitative technique in different study setups: content analysis , case studies and in-depth

interviews, self-ethnography , expert co-design workshops and ethnographic field studies. In terms of the analysis, I applied thematic analysis methodology through my research to describe patterns across my qualitative data, following the procedure developed by Braun and Clarke [7]. While trying to specify my research of interest and main research question during my research, I wanted to diversify my methods of inquiry, as Table 1. Illustrates.

4 CASE STUDIES

In this subsection, I explain research question(s), objectives, methods and outcomes, deliverables and my reflections in detail. Table 1. also summarizes the mapping and the distribution of the studies.

4.1 Examining Online Practices of an Autism Parent Community in Turkey: Goals, Needs, and Opportunities (DIS 2019, Full Paper)

https://dl.acm.org/doi/pdf/10.1145/3322276.3322344

In this study, I used digital ethnography methodology. Through a detailed digital ethnography of one month of interaction flow between parents (posts and comments) in a large and very active Facebook group, I revealed how the platform functions for parents in terms of exchanging access. This study revealed that the interactions of parents in a support group are mainly dominated by medical discourse, which stands as a limited perspective to understand everyday lived experience of autism parenting. Based on my insights in terms of the functions of the platform for parents and their interaction patterns, I came up with recommendations for such socio-technical mechanisms (e.g. Facebook) to support parents to discuss their bottom-up, diverse experiences of everyday living with autism beyond the medical diagnosis. First, socio-technical mechanisms should allow collective redefinition of autism, beyond medical definitions by opening a space to negotiate medical discourse and empower caregivers within medical discourse. One of the ways to empowerment is through civic engagement, as it is discussed in the article.

4.2 An Institutional Perspective: How Gatekeepers on a Higher Education Interact for the Organization and Distribution of Access (under revision for e-CSCW 2022, Full paper)

In this case study of a higher education institution, we conducted in-depth semi-structured interviews with the gatekeepers. This study allowed me to rethink gatekeeping around access at institutional level and how socio-technical mechanisms at this level can shape the organization and distribution of access. Here, we reveal how gatekeepers interact and collaborate around existing institutional collaborative systems to collect and distribute access in the higher education setting. Our data shows that existing collaborative systems (collaborative technologies and interaction patterns -or lack of them-) come with institutional challenges hindering equity and inclusion for members with disabilities. Key issues revealed through our findings are (1) the non-shared definitions around access, (2) lack of tools for experience documentation, (3) ineffective feedback loops around access requests, (4) impact-based prioritization technologies for access requests. We discuss how our analysis contributes to equity-oriented future collaborative system design around organizing higher education access at the institutional level.

RQ	RQ1 (Online group)	RQ2 (Higher education case study)	RQ3 (Design research spaces)	RQ4 (Higher education, reorganization)	RQ5 (Expert group, city)
People Involved	Mixed abilities	Mixed-ability gatekeepers (mostly non-PwD)	Person with a disability,	Mixed-abilities	Mixed-abilities (mostly PwD)
Interaction	Bottom-up Online	Institutional Offline	Bottom-up & Institutional Offline	Bottom-up Offline	Bottom-up & Institutional Offline
Power hierarchy within the group	Unequal power distribution	Unequal power distribution	Unequal power distribution	Equal power distribution	Empowered

Table 1: Summary of research questions in terms of 1) people involved in the related WP 2) power hierarchy within the group of people involved 3) which type of an interaction exists between people involved and socio-technical structure.

4.3 Disabled and Design Researcher: An Unexpected Relationship? (DIS 2020, Provocation)

https://dl.acm.org/doi/pdf/10.1145/3393914.3395861

Here, I used an autoethnography methodology. I collected, organized and revealed my experiences around being a design researcher. This work helped me to understand how access is distributed through my various interactions with socio-technical systems in the work environment, such as in the design-lab or in academic conferences. I revealed my experiences as a disabled design researcher through my interactions with socio-technical infrastructure in the design lab that I work, while conducting design research and while interacting with the international research community. To explore how to sustain a non-toxic disabled-design researcher life within this ecosystem, I asked several provocative questions to the HCI community that would open a discussion around supporting more inclusive design research spaces.

4.3.1 An Ethnographic Account on Getting Around the Campus (Ongoing). Through using self-ethnography and extending it with ethnographic methods, I collected data regarding how mixed-ability campus members interact with socio-technical infrastructure on campus to organize access for themselves. How do they use places, tools and technologies to make campus resources and buildings accessible? How do they create accessible experiences for themselves on campus? I discovered various ways of creating everyday accessibility by negotiating, recurating and reorganizing campus infrastructure and resources. This work is planned to be submitted to the Design and Culture journal as a full paper.

4.3.2 Distribution of access by mixed-ability expert group (Ongoing). My ongoing research focuses on the mixed-ability labor who aim to increase equal access via advocacy, activism and consultancy. I am working with a mixed-ability expert group defining themselves as "social enterprise" who consult different organizations, places and events in İstanbul to become more accessible for people with disabilities. In this study, I ask the following research questions: How does the mixed-ability expert group work together to transform their personal experiences around access into professional knowledge? What tools, technologies and mechanisms are used in this process and how are they used? And what challenges do they experience, and how can they be better supported? I plan to submit this work to the International Journal of Design or Design Journal during 2022.

I am in the process of data analysis. I conducted in-depth semi structured interviews with the members of the mixed-ability expert group and conducted field studies during their consultation processes with the organizations.

[Expected] Deliverables: -Design insights to support mixed-ability expert group -Full paper will be submitted to CHI'23

Overall, my research aims to understand the role of socio-technical infrastructures on the organization of access for the mixed-ability collaborators and uncover the power-relations between relatively larger mixed-ability groups that organize access. I try to understand how design of socio-technical systems where the mixed-ability collaborators may challenge this to ensure equal-access for people with disabilities.

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