Expanding Disability Justice in HCI: Considerations of Holistic "Lived Experience"

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Abstract:

What would it take for HCI research to hold a stronger disability justice perspective? What is missing? While disability-justice-related research is receiving increased attention in HCI in recent years [1], HCI still broadly lacks consideration of the multiple mechanisms and different interactions resulting from different types of disabilities and associated co-morbidities. These mechanisms and interactions include the considerations of physical, biological, psychological, psycho-social, cultural, and emotional interactions that create the holistic "lived experience" of a disabled person [2, 3]. For instance, in addition to the epistemic (methods and scope) injustice [1] that people with disability experience within HCI research, there are inadequate practices and norms of communicating the actual abilities and related challenges of the disabled participants in contemporary HCI literature [4, 5]. Additionally, disability research in HCI primarily focuses on the paradigms of physical abilities, treatment, and "healthism," which make this population "marginalized" or excluded in the scopes of other life aspects [6, 7] (e.g., personal finances, personal informatics). Further, traditional forms of HCI research do not provide guidance on appropriate methods, ethics, and protection for the emotionally sensitive contexts of disability, including unexpected transitions of life due to disability, declining ability, or effects of multiple disabilities of the participants – putting both participants and researchers at risk. Notably, recent HCI researchers advocated for the "*critical realist*" viewpoints of disabilities, acknowledging that the disabled experience is multi-faceted and far more complex than the functional limitations of people. Similarly, Mankoff et al.'s [2] critical reflection on disability theories provided the nuance that instead of focusing only on technical merits of accessibility, assistive technology should take a non-reductionist perspective – considering multiple aspects of interactions related to the complex disabled experience. Therefore, human-centered approaches should consider and involve these missing aspects of participants' holistic "lived experience" in future disability studies to expand disability-justice in HCI.

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