Research Through Design with Differently Abled People: Participation, Ownership and Equitable Conclusions

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Position Statement

There has been a long trajectory of work in HCI research on supporting marginalized groups through affirmative actions. Muller et al., suggest that one of the primary focuses in Human-Computer Interaction (HCI) lies on the social responsibility of bringing diverse populations with different characteristics, such as older adults, children, culturally minor communities and especially, people with disabilities [9]. The HCI community has a history of engaging with diverse communities of differently abled people. Yet, early attempts of supporting people with disabilities have some shortcomings that have resulted in a high abandonment rate of assistive devices [3]. There are multiple issues contributing to this trend that include the typical long process of adopting new technology to reach people with disabilities [11], high cost of assistive devices, and devices that do not adequately support the end user's needs [4].

Recently, Bennett and Rosner [1] emphasized that it is not enough to empathize through mimicking or 'prototyping' the experiences of people living with disability. Instead, as a more considerate approach, the authors urge designers to acknowledge the capabilities of people with disabilities by "being with" them and working as close collaborators. Similarly, Power et al. [11] emphasize a "pluralistic approach" that promotes

participation of people with disabilities to lead their own "inclusive experience" and the "diversity of lived experience".

In our own ongoing research, we are adopting a Research through Design (RtD) approach that is heavily influenced by Participatory Design [8] to the creation of new design artifacts and systems. Our research interest intersects with the perspective of moving away from "[designing] with sight in mind" [7]. Our focus is on how to better support the experience of reminiscence for people living with blindness; an area that has been an ongoing area of HCI research but which has largely overlooked differently abled populations. Our research goal is threefold. First, we aim to provide an in-depth understanding on the experience of reminiscence for people living with blindness, including; personal practices, cherished artifacts, social interactions, challenges and desires. Second, based on the findings, we plan to co-speculate design ideas and opportunities for interactive technology to support experiences of reminiscence for people living with blindness with participants. Third, we will create a research product [10] that is intended to be lived with participants for a longer period of time in their everyday lives. Through our research, we aim to explore how technology could enrich experiences of reminiscence, reflection and social connection for people with blindness. We have completed the first stage of the research so far, which is submitted and accepted as a Work-In-Progress paper for DIS '20 [13].

Our motivation for participating in this workshop is to discuss questions and to share emergent dilemmas that we have discussed and reflected on through our RtD process in engaging people living with blindness. Our goals are to propose discussions around main concerns for this workshop in relation to RtD and differently abled people to better understand how other researchers have coped with their concerns and dilemmas when conducting RtD with different and potentially marginalized or sensitive populations. Our discussion topics fall in three areas; participation, ownership and equitable conclusions.

Participation
Many design techniques and methods are used to encourage engagement from end user population via design-oriented approaches (e.g., Cultural Probes [6], Speculative Enactments [5], Experience Prototyping [2], Participatory Design [8]). Some researchers have created a novel approach to evaluate experiences of interacting with technology for autistic children [12]. Yet, it is not clear that how we should best adapt these techniques for to engage with different abled populations in ways that are sensitive, appropriate, and generative. As design researchers, how do we design appropriate settings, activities and questions? How do we have effectively reach the right level of 'appropriateness' for a given person or population in this context? Is it possible to adopt protocols, designed for other target groups with a different kinds of differently abled people or populations? In our view, these questions lead to the larger question of design research that intends to encourage participation of and with different abled people.

Ownership
Recognizing and appreciating participants is also an important part of the research process. Yet, published academic work is often intended for an academic

audience and is not well setup to be directly translatable to research participants. Additionally, some participants may find the academic findings and publications are challenging to access. In order to achieve a broader distribution and impact, what are appropriate approaches to adopt in an RtD process to ensure that differently abled research participants receive some form of direct value or benefit for their participation? What is a proper way of 'giving it back' to the participants?

Equitable Conclusions
To date, there is limited work in the HCI community has conducted longer-term field research to uncover and design for experiences and desires for differently abled populations through an RtD process. If a research prototype has offered a notable difference in participants' everyday lives or in their experience in a specific context, how do we equitably conclude the project when it inevitably comes to an end? How would or should deployed research prototypes or research products be collected back? Removing a design artifact from participants lives may lead negative experiences or consequences. Prototypes and products created through an RtD process are uniquely designed for participants and rarely have a replacement that would offer a similar experience. Alternatively if participants end up keeping a design artifact, how should ongoing maintenance be handled during and long after the deployment field study?

Lastly, in the workshop we aim to discuss and reflect on the potential impact of RtD in this context. Being differently abled is not a characteristic that uniquely defines a participant group or a single research participant. Research participants' backgrounds,

personal experiences, challenges and desires are not the same. Considering this matter, would outcomes from field studies RtD artifacts be scalable and generalizable?

It is our desire to discuss one or several of these topics and to explore potential intersections across research interests and experiences of fellow researchers. These concerns are hard to answer. Yet, we believe that discussion would enable the community of RtD practitioners to explore ethical and methodological issues that are and will continue to be of growing concern in the fields of HCI and design.

Acknowledgements

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