

Hilda Tellioglu (2024): Challenges in Participation of Vulnerable Groups in Design Processes. In: Proceedings of the Workshop on Practices of Participation and Co-Creation in Healthcare: Lessons Learned and Advancements of Established Methodologies at the 22nd European Conference on Computer-Supported Cooperative Work: The International Venue on Practice-centered Computing on the Design of Cooperation Technologies – Reports of the European Society for Socially Embedded Technologies (ISSN XXX-XXXX), DOI: 10.18420/ecscw2024-to-be-added

Challenges in Participation of Vulnerable Groups in Design Processes

Hilda Tellioglu

TU Wien, Artifact-Based Computing & User Research

hilda.tellioglu@tuwien.ac.at

Abstract. This position paper is based on experiences of and analyses from two different research projects, as the source from which challenges are drawn and solutions suggested for discussion at this workshop.

In design collaborations, a number of participants can work hand in hand with one another in as many stages as possible in order to realize an end goal. This is very much dependent on communication between participants, mutual respect, and a shared understanding of objectives. The generic process of collaborative designing with requirements among the actors in ensuring success is presented below: The initiation and alignment, which will have a clear objective setting and role and responsibilities definition; research and exploration as information sourcing and collective share and synthesis; ideation and conceptualization, by use of a brainstorming and co-creation workshop; prototyping and testing through the development of prototypes with iterative feedback. This follows the finalization of design and refinishing of development, which follows the assessment of the outcomes and planning of how best to improve in the future.

In design collaborations with vulnerable groups, the described collaboration situation is a little bit more challenging. Even if one can argue that the collaboration

with end users should happen on an equal footing if the end users are people with special mental or physical needs designers have to consider several collaboration aspects and prepare the base for a smoother and easier cooperation. The following aspects are the result of the analysis of collaboration work with vulnerable groups in two different research projects: PHOBILITYaktiv (2018-2020, to enable equal mobility for persons who suffer from anxieties, phobias, and compulsory disorders which also implies equal participation in social life) and “Skill-sharing for young people with disabilities” (2022, to explore ways in which young people and young adults with mental disabilities can be supported in passing on their skills).

- *Open communication* about the issues of design is important to provide effective channels and regular schedules for communication to ensure everyone is updated and misunderstandings are minimized. In the case of cooperation with a vulnerable group, the ways of open communication need to be considered each time carefully in order not to promise too much about the features or possibilities in interaction with the system-in-development.
- A successful collaboration is based on the *trust* vested in the abilities and inputs of each of the collaborators and *respect* for their differing perspectives and expertise. One can, in a manner either consciously or unconsciously, underestimate the abilities and inputs of participants with disabilities. This will not be due to a scrutiny of the actual abilities and capabilities but a preconceived notion of their limitations. For example, they could communicate in a different way. For instance, one is bound to meet a participant who has a cognitive disability that is unable to articulate ideas in usual ways, a participant who has a speech impairment that is not understandable during spoken conversations, among others, and other communication variations that can constrict views. The last group of people may not express or have their views supported well. Disabled participants can be perceived differently and can be treated in a certain way by other team members. The stigma of biases related to disabilities can reflect how other team members perceive and act toward the disabled participants. It can create a feeling of disesteem or lower self-confidence in professional capabilities.
- A *shared vision* and *mutual goals* permit a common view of what the project is supposed to achieve and are therefore used to direct all the effort toward these common goals. The format and language for these visions and goals may differ. All these translations must ferret out concerns being expressed by participants on some matter or value, out of which an effective design solution could be derived for system design. This might take some time, but the result is very worthwhile.
- Working with people with special needs requires an appreciation of different opinions and backgrounds in a bid to foster creativity and innovation. There are several challenges to the *appreciation* of such *diversity*. It is often challenging to ensure proper integration of the different insights due to the possible barriers in communication, accessibility, and

underrepresentation. Such challenges would work against a group benefiting fully from unique perspectives that enhance creative outcomes.