

# Reflections on Ableism in Participatory Technology Design

Kathrin Gerling  
kathrin.gerling@kuleuven.be  
KU Leuven  
Leuven, Belgium

Kay Kender  
silvia-kay.kender@tuwien.ac.at  
TU Wien  
Vienna, Austria

Katta Spiel  
katta.spiel@tuwien.ac.at  
TU Wien  
Vienna, Austria

Saskia Van der Oord  
saskia.vanderoord@kuleuven.be  
KU Leuven  
Leuven, Belgium

Dieter Baeyens  
dieter.baeyens@kuleuven.be  
KU Leuven  
Leuven, Belgium

Arno Depoortere  
arno.depoortere@kuleuven.be  
KU Leuven  
Leuven, Belgium

Maria Aufheimer  
maria.aufheimer@kuleuven.be  
KU Leuven  
Leuven, Belgium

## ABSTRACT

Participatory efforts to design technology for disabled people often involve a range of stakeholders, but we rarely pause to question how perspectives and views of the different people involved in those processes - including negative or incorrect perceptions of disability - influence our work. In this paper, we explore how ableism, i.e., discrimination based on normative bodily assumptions mostly affecting disabled people, impacted our research projects, and outline challenges for our research communities moving forward.

## KEYWORDS

Ableism, Disability

## 1 INTRODUCTION

The Human-Computer Interaction (HCI) research community typically views participatory approaches toward technology design as a means of creating systems that are better attuned to the intrinsic needs of people engaging with them [2]. Particularly when working with marginalized people (e.g., disabled people, children or older adults), the democratic notion of participatory design is interpreted in a way that suggests that resulting artefacts are an accurate reflection of their preferences and needs, facilitating the creation of *empowering* technology (e.g., see [9, 15]; also our own work, e.g., [7, 14] for research projects applying this reasoning). At the same time, there is understanding that participatory design is a complex process that needs to be employed with care. For example, Brateteig and Wagner [3] extensively discuss the relevance of power issues between participants and the need to mitigate those, and Harrington et al. [10] reflect on the privilege of participation and the potential of participatory processes to induce harm. Likewise,

a recent exploration by Williams and Gilbert [16] revealed that there is little critical interrogation of how the implicit views and attitudes of researchers and proxy stakeholders who are invited to take part in these design processes shape conversation, and in turn impact technical artefacts. The authors conclude that participatory design in technology design is not in fact always ethical, and should therefore be subject to careful consideration. This goes along with a general push for more inclusive human-centered research methods [13].

In the context of disability, we pick up on Williams and Gilbert [16] and their reflections on the concept of ableism, which we believe offers a useful perspective for critical interrogation at the level of individual research projects. It is succinctly defined by Campbell [5] as *"a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is then cast as a diminished state of being human."* In HCI research, it can offer a lens to further unpack implicit attitudes and biases toward disability and disabled people that impact participatory processes, and, by extension, the technical artefacts that are created in this way. We hope that it can help our research community examine how participants (including disabled participants who have internalised the systemic ableisms around them) and researchers view disability, how these views might trickle down into participatory processes, and in turn become ingrained in technology designs. We illustrate this approach through post-hoc examination of our research projects. Drawing from these examples, we summarize challenges and reflect on potential strategies to uncover and account for the harmful impact of ableism in participatory technology design as our field moves forward.

## 2 REFLECTION ON INSTANCES OF ABLEISM IN OUR WORK

Here, we reflect on two different projects addressing neurodivergence and neurodivergent people through technology, and the role that ableism played in our work.

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the owner/author(s).

Veröffentlicht durch die Gesellschaft für Informatik e.V.

in K. Marky, U. Grünefeld & T. Kosch (Hrsg.):

Mensch und Computer 2022 – Workshopband, 04.-07. September 2022, Darmstadt

© 2022 Copyright held by the owner/author(s).

<https://doi.org/10.18420/muc2022-mci-ws11-219>

## 2.1 Project 1: A Game-Based Societal Intervention to Teach About ADHD Through Games

Three of us are part of an ongoing funded project exploring how to create societal interventions to improve knowledge of and attitudes toward young people with ADHD. The project involves adolescents with ADHD directly in the creation of such solutions, and explicitly does not suggest that neurodivergent people need to adapt to conform with neurotypical behaviours. Yet, we were surprised to observe multiple instances where research participants constructed their own identities against the backdrop of expressions of neurodivergence and disability that they perceived as *worse than their own*. For example, participants commented that they *only had ADHD and it was not like they were autistic*, or explicitly pointed out that *they are not disabled*. This suggests that they had possibly internalized negative societal attitudes toward disability [4]. Additionally, the same project involved a range of additional experts, including adults with ADHD. Here, we saw instances where they *questioned the experiences of young people with ADHD*, who reported an overwhelmingly negative perspective, pointing out that ADHD also included strengths such as hyperfocus, which they suggested we include in our intervention. We extensively discussed within the research team how to balance the perspective of young people and adults with ADHD, and concluded that we had to prioritize the lived experience of young people, accepting that particularly for young people in school, there is little room for agency, and hence substantially less opportunity for self-determination and the experience of being able to intensely focus on an activity. We still are not entirely sure whether this was the right decision, but the instance reminded us of our own previous work on interactive systems to support wheelchair skills training among young people [8], where proxy stakeholders made fundamentally wrong assumptions about the experiences and abilities of young wheelchair users. Overall, this highlights the complexity of participatory technology research and the impact of ableism, suggesting that it needs to be carefully unpacked to create appropriate spaces for research, and to interpret research outcomes correctly.

## 2.2 Project 2: Designing for Social Play with Neurodivergent Children

Two of us joined a research team that had received funding by the Austrian Science Fund (FWF) to design digital playthings with neurodiverse groups of children<sup>1</sup>, on the premise that social play is key for the successful inclusion of children with disabilities and has significant impact on their wellbeing and development, i.e. of (neurotypical) social skills [6]. Although two of our three final prototypes were successful in facilitating social play, and the children we worked with reported being proud of their design and having fun, the more we got to know our participants<sup>2</sup>, the more we questioned whether it was the right approach to design technologies that persuade children who may not feel the need to play with others to do so. In hindsight, the very assumptions our project goal

<sup>1</sup>This means that both neurodivergent and neurotypically presenting children were involved in mixed groups.

<sup>2</sup>and for [removed for review], who was new to both participatory design and autism: the more I learned about participatory design and autism

rested on were questionable, built on a neurotypical paradigm of what social play is, how much of it is necessary, and for whom. Other possibilities that may have aligned better with the wishes of the children we designed with became evident, for instance finding a way to deploy technologies to support appreciation for solitary play. However, given the felt constraints of the funding body, the (neurotypically informed) promises we assumed we had to keep and the disciplinary position of the research project, we had the impression that we would be limited in actually doing so. Subsequently, we did not even try.

To reflect on this project is to reflect on the double-edged sword of aiming to enact participatory design within a fundamentally ableist society. On a project level, on the one hand, there are currently (and for the foreseeable future) real advantages to learning a neurotypical skillset (e.g., camouflaging or masking, social etiquette and processes, emotion recognition) – on the other, this supposes and perpetuates a world in which everyone must adapt to the dominant group and requires neurodivergent people to perform additional work, work that has been shown to be actively harmful [1]. On the one hand, our research was heavily oriented on participants [11] and thus led to the development of genuinely engaging digital playthings, on the other, it was funded based on inherently ableist assumptions and its successful accomplishment perpetuated these to some extent.

## 3 CHALLENGES MOVING FORWARD

In moving forward, there are four main challenges where we see a need for them to be addressed: **(1) Carefully Unpacking Internalized Ableism.** When working with disabled participants (or as disabled researchers), we need to actively create the space to reflect upon their and our attitudes and views, and how they might influence the research process and outcomes thereof. **(2) Addressing Ableist Views Among Proxy Stakeholders.** When involving proxy stakeholders, we need to carefully examine their perspectives on disability and the people who they intend to represent, and we need strategies to address instances of ableism in a constructive way. **(3) Interrogating Biases Within Research Teams.** We need to accept that ableism also exists within research teams, even when directly involving disabled researchers, and can have a profound impact on the shape of research processes and technological artefacts. We need to develop practices of continuously interrogating views and perspectives within the research team. **(4) Challenging Ableist Assumptions Underpinning Funding Schemes.** One observation that we made across projects is how government policies, funding schemes, and calls shape research projects, and can sometimes inject ableist views from the very start. Here, research communities should pay close attention to underlying assumptions, and be mindful of the systems that they buy into.

Many of our observations directly relate to findings by Williams and Gilbert [16], further supporting the notion that implicit views and attitudes among participants, proxies and researchers may have profound negative implications for disabled people because resulting technical artefacts do not meet their needs, solidify existing ableist ways of thinking, or simply because opportunities for better, more appropriate research are missed. This is particularly relevant as projects that are designed to be *participatory* do not always offer

real participation in the sense that *power over the research direction* would be shared, risking that disabled participants become complicit in the creation of artefacts that are of questionable benefit for their own communities, and reinforce rather than alleviate oppressive structures. Overall, we conclude that research teams need to familiarize themselves with the concept of ableism to interrogate, recognize, and manage its occurrence in participatory research efforts. For example, one step toward this could be the application of strategies that challenge and re-engage our internalized ableism (e.g., through mirroring and humour in [12]), educating us on and continuously reminding us of our own biases and views. We very much look forward to discussing this and other possible strategies in the context of the workshop.

## ACKNOWLEDGMENTS

The authors of this work are funded through different channels, including grant T 1146-G by the FWF, and grants G057320N and 11E9122N by the FWO. We also want to acknowledge the contribution of all research participants to our work, whom we thank for their time and for sharing their perspectives and insights.

## REFERENCES

- [1] Jonathan S Beck, Rebecca A Lundwall, Terisa Gabrielsen, Jonathan C Cox, and Mikle South. 2020. Looking good but feeling bad: "Camouflaging" behaviors and mental health in women with autistic traits. *Autism* 24, 4 (2020), 809–821.
- [2] Erling Björgvinsson, Pelle Ehn, and Per-Anders Hillgren. 2010. Participatory Design and "Democratizing Innovation". In *Proceedings of the 11th Biennial Participatory Design Conference* (Sydney, Australia) (PDC '10). Association for Computing Machinery, New York, NY, USA, 41–50. <https://doi.org/10.1145/1900441.1900448>
- [3] Tone Bratteteig and Ina Wagner. 2014. *Disentangling Participation: Power and Decision-making in Participatory Design* (1st ed.). Springer.
- [4] Fiona A. Kumari Campbell. 2008. Exploring internalized ableism using critical race theory. *Disability & Society* 23, 2 (2008), 151–162. <https://doi.org/10.1080/09687590701841190> arXiv:<https://doi.org/10.1080/09687590701841190>
- [5] Fiona Kumari Campbell. 2009. *Contours of Ableism: The Production of Disability and Aabledness* (1st ed.). Palgrave Macmillan London.
- [6] Christopher Frauenberger, Kay Kender, Laura Scheepmaker, Katharina Werner, and Katta Spiel. 2020. *Designing Social Play Things*. Association for Computing Machinery, New York, NY, USA. <https://doi.org/10.1145/3419249.3420121>
- [7] Kathrin Gerling, Kieran Hicks, Michael Kalyn, Adam Evans, and Conor Linehan. 2016. Designing Movement-Based Play With Young People Using Powered Wheelchairs. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (San Jose, California, USA) (CHI '16). Association for Computing Machinery, New York, NY, USA, 4447–4458. <https://doi.org/10.1145/2858036.2858070>
- [8] Kathrin Gerling, Kieran Hicks, Olivier Szymanczyk, and Conor Linehan. 2019. Designing Interactive Manual Wheelchair Skills Training for Children. In *Proceedings of the 2019 on Designing Interactive Systems Conference* (San Diego, CA, USA) (DIS '19). Association for Computing Machinery, New York, NY, USA, 725–736. <https://doi.org/10.1145/3322276.3322281>
- [9] Foad Hamidi, Patrick Mbullo, Deurence Onyango, Michaela Hynie, Susan McGrath, and Melanie Baljko. 2018. Participatory Design of DIY Digital Assistive Technology in Western Kenya. In *Proceedings of the Second African Conference for Human Computer Interaction: Thriving Communities* (Windhoek, Namibia) (AfricHI '18). Association for Computing Machinery, New York, NY, USA, Article 8, 11 pages. <https://doi.org/10.1145/3283458.3283478>
- [10] Christina Harrington, Sheena Erete, and Anne Marie Piper. 2019. Deconstructing Community-Based Collaborative Design: Towards More Equitable Participatory Design Engagements. *Proc. ACM Hum.-Comput. Interact.* 3, CSCW, Article 216 (nov 2019), 25 pages. <https://doi.org/10.1145/3359318>
- [11] Kay Kender, Christopher Frauenberger, Johanna Pichlbauer, and Katharina Werner. 2020. *Children as Designers - Recognising Divergent Creative Modes in Participatory Design*. Association for Computing Machinery, New York, NY, USA. <https://doi.org/10.1145/3419249.3420145>
- [12] Kay Kender and Katta Spiel. 2022. FaceSavr: Designing Technologies with Allistic Adults to Battle Emotion Echolalia. In *CHI EA '22: CHI Conference on Human Factors in Computing Systems Extended Abstracts* (New Orleans, USA) (CHI '22). Association for Computing Machinery, New York, NY, USA, Article 14, 8 pages. <https://doi.org/10.1145/3491101.3516383>
- [13] Kelly Mack, Emma McDonnell, Venkatesh Potluri, Maggie Xu, Jaily Zabala, Jeffrey Bigham, Jennifer Mankoff, and Cynthia Bennett. 2022. Anticipate and Adjust: Cultivating Access in Human-Centered Methods. In *CHI Conference on Human Factors in Computing Systems* (New Orleans, LA, USA) (CHI '22). Association for Computing Machinery, New York, NY, USA, Article 603, 18 pages. <https://doi.org/10.1145/3491102.3501882>
- [14] Julia Makhaeva, Christopher Frauenberger, and Katta Spiel. 2016. Creating Creative Spaces for Co-Designing with Autistic Children: The Concept of a "Handlungsspielraum". In *Proceedings of the 14th Participatory Design Conference: Full Papers - Volume 1* (Aarhus, Denmark) (PDC '16). Association for Computing Machinery, New York, NY, USA, 51–60. <https://doi.org/10.1145/2940299.2940306>
- [15] Laurianne Sitbon and Shanjana Farhin. 2017. Co-Designing Interactive Applications with Adults with Intellectual Disability: A Case Study. In *Proceedings of the 29th Australian Conference on Computer-Human Interaction* (Brisbane, Queensland, Australia) (OZCHI '17). Association for Computing Machinery, New York, NY, USA, 487–491. <https://doi.org/10.1145/3152771.3156163>
- [16] Rua M. Williams and Juan E. Gilbert. 2019. *Advancing Diversity, Inclusion, and Social Justice Through Human Systems Engineering* (1st ed.). CRC Press, Chapter "Nothing About Us Without Us" Transforming Participatory Research and Ethics in Human Systems Engineering. <https://doi.org/10.1201/9780429425905>