
Individuality over function: the role of technology in disability identity

Giulia Barbareschi

University College London
Interaction Centre, Computer Science,
66-72 Gower Street, WC1E 6BT, UK
giulia.barbareschi.14@ucl.ac.uk

Dafne Zuleima Morgado Ramirez

University College London
Interaction Centre, Computer Science,
66-72 Gower Street, WC1E 6BT, UK
d.morgado-ramirez@ucl.ac.uk

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Abstract

When designing or investigating technology use among people with disabilities, researchers often overstate the importance of functional aspects at the expenses of identity. We present three case studies that showcase how people with disabilities use, or aspire to use, technology to advertise, reframe or hide their identities.

Author Keywords

Disability; technology; identity; society; wheelchair; prosthesis; visually impaired

CSS Concepts

• **Social and professional topics** ~ **User characteristics** ~ **People with disabilities** • Human-centered computing ~ Interactions design ~ Interaction design process and methods ~ Participatory design

Introduction

Within the last decade the HCI community has witnessed an increasing interest in the topics of disability and technology. Within and outside the collection of CHI proceedings, there are many valuable contributions that acknowledge how technology can be a valuable tool for empowerment when people with disabilities are actively included in its conceptualization and development [2,4]. However, most of the work

Methods of Case Study 1

10 Visually impaired participants were engaged in a co-design workshop that featured two speculative exercises storytelling and clay modelling. During the storytelling exercise participants were asked to describe a future in which technology could enable a child with visual impairment to live their life in the way they wanted.

Methods of Case Study 2

Semi structured interviews and observations with: 8 expert wheelchair users, who trialed the new prototypes, and 6 clinicians and x wheelchair technicians, who manufactured the new wheelchair prototypes.

done by the HCI community around disability and technology is mainly focused on the functionality of the technology designed for, designed with or used by people with disability. Aspects concerning social interactions, embodiment, culture and identity are often only given a secondary role.

In their work [7,8], have highlighted how people with disabilities make complex decisions about which technology and when to use it based on how they thought the appearance of the technology would reflect on them. Their findings emphasize how being perceived as efficient, professional and their most able self was important for many people with disabilities and affected the choices they made. On the other hand, findings from [1], show how concepts of function and identity are not only deeply intertwined in the interaction between technology and people with disabilities, but they are also fluid concepts that constantly change based on the individual's preferences.

Considering identity is crucial to critical disability studies as people with disabilities are becoming tired of societal pressures that attempts to normalize them, sometimes through technology, denying the value that lies in diversity often at high personal and societal costs [6]. In this paper we present three short case studies from past and ongoing research projects that showcase how people with disabilities use, or aspire to use, technology to advertise, reframe or hide their identities in the context of disability.

Throughout all three case studies our focus was to engage participants on an equal basis, abolishing power gradients between researchers and participants and leveraging what people can do rather than what they

can't [3]. To do this we established strong connections with local universities and Disabled People Organizations and worked alongside community researchers who were part of the local communities and were often people with disability themselves. The aim is to reduce as much as possible the risk of having a colonialist approach that undermines the African ecosystem and leads to emerging solutions that are modeled on Western values [5].

Case study 1: speculative design with people who are visually impaired in informal settlements in Kenya

The aim of this study was to understand how the social infrastructure of people with visual impairments who live in informal settlements in Kenya affects the way in which they use mobile and digital technologies. We explored the future interactions that participants aspired to have with technology.

Findings

In the imaginative futures depicted by participants, technology was seen to play an important role in creating an environment where people with visual impairment could thrive. Despite the inclusion of "functional" technology that was directed as the person with disability (e.g. talking canes), participants highlighted how technology will help their non-disabled peers to gain information about disability, so that they would become more inclusive towards people with disabilities. From the modelling exercise, a notable finding and the most well received technology idea was an "intelligent traffic light" that, when the person with disability pushed the appropriate button, would alert the drivers of the fact that the person might need additional time to cross the road safely.

Methods of Case Study 3

One week-long scoping studies in each country were performed consisting of informal chats with people with amputation or congenital limb absence as well as visits to local private and public clinics and hospitals known for providing prosthetics delivery services. The scoping study helped to shape semi-structured interviews guidelines culturally aware and in four languages: English, Luganda, Soga and Jordanian Arabic. 17 people with amputation in Uganda and 10 people with amputation and five people with congenital limb absence in Jordan were interviewed.

Implication for identity

In Kenya disability stigma is pronounced. In large parts of the country Disability Rights movements and the social model of disability are non-existent and people with disabilities are still seen as individuals who should be “fixed”. Admittedly, we expected participants to dwell on the role that technology could play in overcoming their physical impairments. Instead, they shifted towards giving information to non-disabled people, creating a better understanding of disability and enabling others to adapt their behaviors according to the circumstances. In the example of the traffic light, participants sought to cross the road quicker but wanted to advertise their identity so that drivers would adjust their expectations and drive more inclusively.

Case study 2: 3D printing bespoke wheelchairs in Kenya

The purpose of this project was to test the feasibility and acceptability of using a combination of 3D printing technology and local manufacturing techniques to build custom made quality wheelchairs in Kenya with the aim to reduce the need for mass importation and improve the quality of locally available products.

Findings

Despite some limitation in functionality, participants’ opinions about the new wheelchair prototypes were overwhelmingly positive. Most users praised the appearance of the wheelchair, using terms such as “sexy”, “attractive” and “fun”. Participants felt that the new wheelchair could help them project their self-selected image and they were pleased about the possibility of having a wheelchair that, like themselves, was truly unique. The analogy of getting a tailor-made dress vs. going to a store was made to compare this

novel provision model compared to the more traditional one that is common in Kenya.

Implication for identity

Work by Bennett et al 2016 has already shown how prosthetic devices can become integral part of the body image that amputees have of themselves and the one they wished to share with others. Our preliminary findings show that wheelchair users share very similar experiences, but because of the limitations of available devices, they have less chances to present themselves in the way they want. In their eyes, one of the most valuable aspects of these bespoke wheelchairs was the ability to have a device that enabled them to reframe their identities in a more positive way - reclaiming their individuality.

Case study 3: upper limb prosthetics in Uganda and Jordan

The overall main research project called “Fit-for-purpose, affordable body-powered prostheses” has set to design a fit for purpose upper limb prosthetic for Uganda and Jordan respectively. There is an unknown number of people with amputations or congenital limb absence in Uganda and Jordan. One working package aimed to understand the life experience, needs and preferences of people that use (or need but cannot access) upper limb prosthetics.

Findings

Participants in both countries shared experiences of ableism, which was illustrated in terms of heightened staring, heightened pity, reducing the humanity of people with limb loss, intense and cumbersome curiosity with intense questions, exclusion, discrimination and social pressure to seek a prosthesis.

Our contribution to the workshop

Share our experience on how people with disabilities can use technology to advertise their identity, reframe it or hide it. These experiences contribute to expand the discussion in Critical Disability studies around identity and embodiment in relation to assistive technology. In this context technology can be seen as an extension of the body phenomenological nature, a way to affirm or deny disability depending on the specific socio-historical conditions of people with disabilities in lower resourced settings.

Our expectations from the workshop

To interact with other researchers who value the use of critically disability studies in the design and in the analysis of research. To contribute towards a manifesto to motivate HCI researchers to utilize critical disability studies in their work.

People in both countries want the prosthetic to match their skin color and its size to be in relation to the rest of their body. Appearance over functionality is preferred. They consider that a cosmetic prosthetic should look as natural and realistic as possible, so the prosthetic becomes a technology that hides the disability, thus preventing ableism and discrimination.

Implication for identity

Given that disability is stigmatized in both countries, people with upper limb loss are making technology choices based on their social and cultural environment instead of their needs. They are utilizing technology to hide their disability. People with upper limb loss in Uganda and Jordan have bigger concerns than accessing a prosthesis and how that prosthesis functions and looks like. They must face ableism and discrimination daily.

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References

- [1] Cynthia L. Bennett, Keting Cen, Katherine M. Steele, and Daniela K. Rosner. 2016. An Intimate Laboratory?: Prostheses As a Tool for Experimenting with Identity and Normalcy. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*, ACM, New York, NY, USA, 1745–1756. DOI:<https://doi.org/10.1145/2858036.2858564>
- [2] Cynthia L. Bennett and Daniela K. Rosner. 2019. The Promise of Empathy: Design, Disability, and Knowing the " Other". In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–13.
- [3] Margot Brereton, Laurianne Sitbon, Muhammad Haziq Lim Abdullah, Mark Vanderberg, and Stewart Koplick. 2015. Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies. *CoDesign* 11, 1 (2015), 4–20.
- [4] Emeline Brulé, Oussama Metatla, Katta Spiel, Ahmed Kharrufa, and Charlotte Robinson. 2019. Evaluating Technologies with and for Disabled Children. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–6.
- [5] Christopher Csikszentmihalyi, Jude Mukundane, Gemma F Rodrigues, Daniel Mwesigwa, and Michelle Kasprzak. 2018. The Space of Possibilities: Political Economies of Technology Innovation in Sub-Saharan Africa. 1–13.
- [6] Dan Goodley. 2013. Dis/entangling critical disability studies. *Disabil. Soc.* 28, 5 (2013), 631–644.
- [7] Kristen Shinohara and Jacob O. Wobbrock. 2011. In the Shadow of Misperception: Assistive Technology Use and Social Interactions. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '11)*, ACM, New York, NY, USA, 705–714. DOI:<https://doi.org/10.1145/1978942.1979044>
- [8] Kristen Shinohara and Jacob O. Wobbrock. 2016. Self-conscious or self-confident? A diary study conceptualizing the social accessibility of assistive technology. *ACM Trans. Access. Comput. TACCESS* 8, 2 (2016), 1–31.