

Leveraging Expertise as Experience in Design

Dr. Rebecca Monteleone
Disability Studies, University of Toledo
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Hello everyone, thank you for having me today. For anyone who cannot see me as well as you'd like to, I am a white woman with short dark hair and plastic frame glasses sitting in front of a window and a bookshelf. If you would prefer to read my presentation today, it is available on my website, RebeccaMonteleone.com.

I appreciate the invitation here today and wanted to take some time, in the midst of this competition, to talk about something I am sure many of you spend a lot of time ruminating on: leveraging the experience of intended end-users as a type of expertise in design. Specifically, I want to focus on users with disabilities, who have historically been left out of these practices, even with the move toward greater participation. To do so, I first want to talk about exactly why design that does not privilege the experiences of users with disabilities is in many cases bad design and in some cases outright harmful. I then want to draw in some insights from my own research interviewing deep brain stimulation recipients about their experiences to highlight the consequences of mismatched priorities and expectations. Finally, I want to close with examples, strategies, and considerations for meaningfully including end users with disabilities into the design process in a manner that is neither exploitative nor tokenizing. Not all of the examples I present will be directly related to neurotechnology, but what I generally refer to as design for disability more broadly. This is an intentional choice as I specifically want to emphasize that the siloing of expertise into these discrete and fiercely guarded disciplines is directly related to issues of usability and desirability of tech.

But before we dive into that, I think it's important to define what I mean by disability. Many of you are likely familiar with a definition of disability (or disabling conditions) that focuses on biological or physiological deficit. I am not referring to a discrete set of biological or physiological characteristics when I use the term, however, but a fluid and contextual position that *includes* the biological, but also the social, political, and cultural dimensions. This is not to say that biological or physiological differences don't exist – of course they do, but to highlight that the binary between disabled/nondisabled, healthy/unhealthy, or well/unwell is not inherent in a body nor predetermined.

Disability, then, is not solely situated in the body but at the interface between the body and a social/political/physical environment designed for able-bodied and neurotypical participation. That interface is, helpfully, the precise place where engineers intervene. I raise these points because that fluid and shifting context is particularly important when thinking about designing for disability. It should not simply mean trying to design with the desire to shift a body out of the "disabled" category and into the "non-disabled" category through bodily or medical intervention, but to take into account how a body experiences the world and how that world – in its physical, social, and political dimensions, might be shifted to meet the body.

An example: someone with a chronic pain condition might define their disability at one point in time in terms of pain – so here disability is embodied. But at another point in time, this same person may define their disability in terms of their inability to access their second floor bedroom now due to having stairs but no elevator or chair lift. In the former understanding, a medical intervention might be considered, whereas for the latter, a change to the environment, not the person, is in order. Considering a medical intervention here doesn't actually line up with the desires of the end user. And importantly, both of these situations may arise with the *same person* as their context and embodied experience changes. Disability is both fluid as a social category (so this division between who is disabled and who is not), but also fluid in individual experience, so making assumptions based on categorical labels is simply insufficient.

Another example: a person with an intellectual disability such as Down syndrome defines their disability by their inability to navigate their local public transit system independently. If we think about disability solely in terms of embodied functional limitations, what are the options for intervention? Research to detect and prevent intellectual disability in the future? These kinds of innovations have no tangible benefit to the person in question, and in fact may pose a risk to their continued existence as it skirts toward eugenics. But if we think about disability as a *social* phenomenon, the disability is located in cultural assumptions of literacy, of cognitive ability, of worthiness to participate, then we open up imaginative alternatives. We can design worlds that fit the people who occupy them rather than changing people to fit into a material and social world that is not as static as we sometimes assume.

Traditionally, as I am sure many of you are already aware design around disability and disabling conditions has been design *for* rather than design *with*. Disability – and the lived experience of disabled people – has been reduced to a list of functional limitations that flatten and objectify bodies with disabilities and encourage design that treats nonnormative bodies as problems to be solved. Science and engineering that has not been attentive to the lived reality of disability has proven to not only be ineffective, in terms of adoption, usability, and abandonment of technology, but contributes to non-inclusive, discriminatory and disenfranchising social and material conditions.

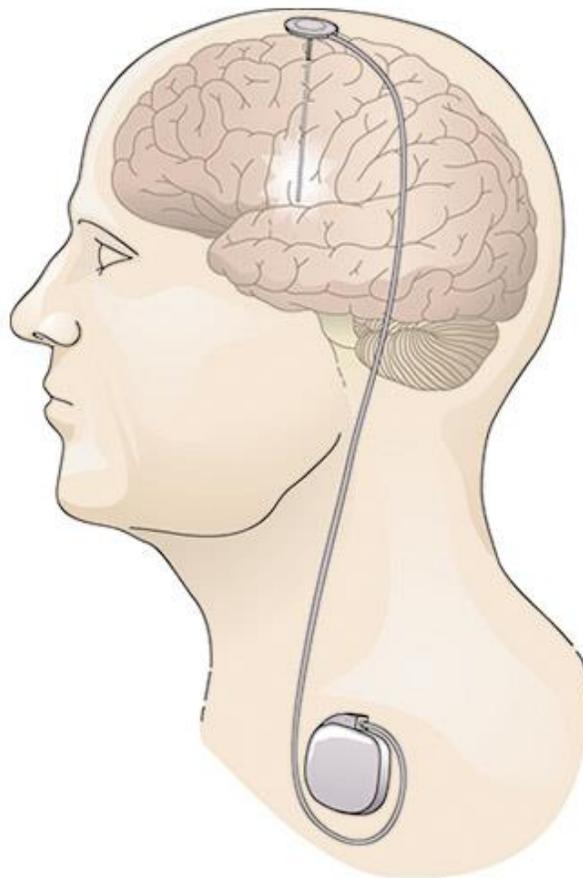
One example of this is what disabled designer Liz Jackson refers to as the “disability dongle.” This is, in her definition, a “well-intended, elegant, yet useless solution to a problem we [people with disabilities] never knew we had.” These kinds of designs are often cutting edge, outrageously expensive, and rarely move beyond a prototyping stage. They usually receive a lot of press attention – often because they are “miraculously” designed by engineers and students who have never encountered a person with a disability. The technologies, which disability activists will be quick to point out are neither useful nor affordable, are positioned as gifts a nondisabled professional is offering the disabled masses – assumed to be helpless and expected to be grateful.



A blonde, smiling woman in ripped jeans rides an electric wheelchair down a flight of cement steps. The chair has additional treads to navigate the stairs. [Source.](#)

One such dogle is the oft-prototyped stair-climbing wheelchair. s.e Smith, a disabled journalist, wrote that this kind of dogle captures the inequitable power imbalances that occur when people with disabilities are excluded from design meant for them. To quote, “technology is pitched as inspirational, showing us how the presumed tragedy of disability can be ameliorated with something invented by someone who is not disabled.” Here, the nondisabled design team are cast as saviors to a despairing disabled public. Wheelchair users however, have repeatedly called attention to inaccessible infrastructure like stairs – rather than advocating for stairclimbers (what s.e. smith remarks are unsafe and unattainably expensive), they call for a much older, much more reliable, and much less expensive option: ramps. As disabled scholar Nivchara Yahel wrote in a Tweet this year after the unveiling of another stair-climbing chair, “Designers who create wheelchairs that climb stairs misunderstand the problem. The problem is the stairs, not the wheelchair.”

Nor does the attention and time funneled into these unusable designs take into account that, according to the World Report on Disability, only 5-15% of the 70 million people around the world who could use a wheelchair have access to one at all, let alone one as expensive as this. Nor does it considered the lived experience of a wheelchair user, many of whom are consistently denied access to basic necessities like caregiving and trained healthcare providers. To editorialize Yahel, the problem *might not even be the stairs*. But without the voices of people with disabilities in the room, it is impossible to actually identify what the problem is – and so often it is assumed that the problem is the disabled person themselves.



A drawing of a head and neck in profile. The head is transparent, showing a brain with a small metal implant connected by a wire to a small silver square near the collarbone. [Source](#).

Drawing on my own research with recipients of deep brain stimulation, the starkly mismatched priorities between users and designers emerges in both big and small ways. One informant, who I will call Mary, repeatedly brought up both her embodied expertise as a person with Parkinson's and the many ways it had been dismissed by the scientific and medical professionals she encountered. For example, she noted that the pulse generator she had implanted in her chest when she received her deep brain stimulator had a squared edge. This shape meant that she is no longer able to shave her armpits, which impacted her self-image and quality of life. She also mentioned a patient remote to adjust the stimulator in development at the time of our interview that was operated by touch screen rather than analog buttons. While this design might ostensibly seem more convenient, Mary suggested that people with dexterity issues – which can be caused by many of the conditions intervened on by deep brain stimulation – are often not able to use touch screens effectively, thus limiting the usefulness of this design. Mary's husband, asserted "If they had talked to the patient first, they would've pointed that out right away. You're going in the wrong direction here." He continued by arguing that "People with Parkinson's should be the ones who are designing these things."

The stakes for exclusive design are not simply device abandonment, but the misrepresentation, belittling, or dismissal of disabled experiences. Ashley Shew discusses this explicitly in the articulation of what she calls "technoableism." She defines it as "a rhetoric of disability that at once talks about

empowering disabled people through technologies while at the same time reinforcing ableist tropes about what bodyminds are good to have and who counts as worthy” (43). Such insight is critical for disability design – calling for a paradigm shift from fixing people to fixing environments. When fixing people becomes central to design, disability tech becomes oppressive. An example of this is the increasing attention being paid to tracking devices for autistic children or adults with dementia. While well-intentioned, these (almost always) non-consensual surveillance devices and the work that they do articulates someone as an issue to be managed and controlled rather than a community member to be included. As more attention is paid to symptom mitigation and/or approximation to able-bodiedness, less attention is paid to personhood.

Another informant who had received deep brain stimulation expressed a similar feeling of dehumanization paired with a preoccupation with functional limitations. Vickie, who had received DBS for an essential tremor, increasingly felt her experiences and opinions invalidated by the clinician responsible for programming her stimulator, who she felt was taking control by making decisions on her behalf. When she felt her clinician was focusing all his attention on her tremors and ignoring both the symptoms, she was most concerned with (difficulty breathing) and the side effects she was experiencing from the stimulator, she expressed her resentment: “His ego was in the way. It was like he had to somehow conquer my brain. And conquer these tremors and make them go away.” The expertise of the scientific professional was not seen as a comfort, but as a source of control. While her experience was with a clinician, the perspective she encountered is not dissimilar to the one that drives motivations behind the development of disability dongles and the like.

People are experts of their own bodies. It is generally taken for granted that person-centered design practices produce more reliably usable results, as does the diversification of scientific and engineering professions. By taking the experiences, desires, and needs of disabled people seriously, we create better technologies, health infrastructure, social systems, and political structures. I look at Dr. Yerbury as an example of someone whose personal life and research are inextricably linked – and the field is better for having him in it.

But people with disabilities have historically been stigmatized, their views delegitimized, and their bodily autonomy compromised in research and design. Knowing these histories of exploitation and invalidation is absolutely crucial for understanding how to change it. As I have written elsewhere, our reflexive practices “must include recognizing the value systems that mobilize communities, publics, and organizations. For healthcare innovations, these systems almost always include models that pathologize and individualize disability, models which undermine disabled perspectives in the deliberative process (Wendell 1996). Reflexivity must also include acknowledgement of power imbalances resulting from or in epistemic contestations, particularly those between medical and experiential knowledge of disability. These imbalances are acutely experienced by people with intellectual and cognitive disabilities, whose perspectives are often deemed nonrational, irrelevant, or non-existent” (2020, 3).

This means that:

- Tokenizing end users by inviting them into the process too far downstream to make any meaningful contributions is not sufficient.
- Inviting people into design processes that are not physically or cognitively accessible is not sufficient.

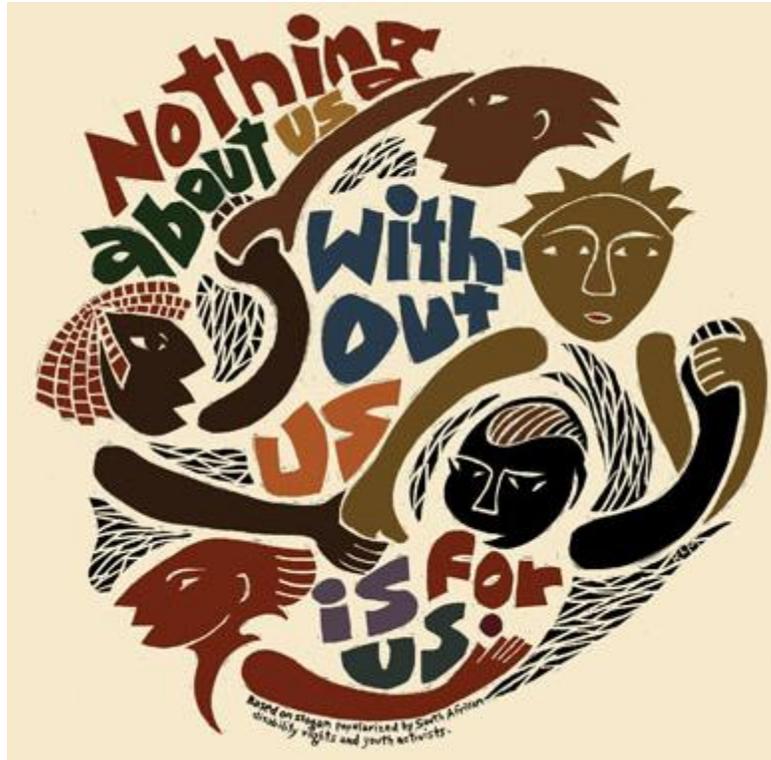
- Privileging design or engineering expertise as more important than lived expertise is not sufficient.

Further, it is important to recognize that many people with disabilities may not have incentives to participate in the development of technological innovations in systems that have exploited and invalidated them. People with disabilities may not trust nondisabled designers in these systems that have historically failed to attend to basic needs, desires and perspectives. Crucially, disabled people *do not owe nondisabled engineers their gratitude, time, or experience*.

The purpose of the kinds of technologies promoted by this competition is ultimately to improve the lives of people with disabilities, in their many forms. Is it not logical, then, that the people you are designing for be the ones to set the research agenda? This paradigm has many names, including co-design and what Gerry Zarb dubs emancipatory research. It is distinguished not necessarily by *how* it is done, but what it accomplishes. Emancipatory research puts the skills and expertise of the designers and engineers *at the disposal of the intended end user*. It is empowering, reciprocal, and transformative because it troubles traditional notions of who controls the research agenda and what becomes of the products of research.

Sara Hendren discusses a radically individualized and low-cost version of this approach in her recent book, *What Can a Body Do? How We Meet the Built World*. She highlights the Adaptive Design Association, a “storefront workshop [that makes] low-cost one-of-a-kind furniture for people with disabilities” in a collaborative process using easy to access materials like cardboard (68). She writes that this approach “isn’t a substitute for standardized devices or the engineering that produces them...rather its focus is on augmentation and alteration – on the entire *ecology* that is required to make the world meaningfully accessible, especially when a quarter of an inch makes all the difference. The tools and materials aren’t just affordable and commonplace; they offer the invitation toward a make-it-yourself disposition and belief that the right modification is out there, within the imaginative grasp of not just experts but networked collaborations of ordinary people.” (91).

Here Hendren calls us to resist the scalability of universalism in favor of a recognition of the situatedness of each person, particularly those who have been most marginalized by able-bodied ideals. This approach requires a richer, more nuanced, and more expansive understanding of knowledge and expertise, of a transformed research paradigm that is mobilized by new kinds of values and utilizes processes open to a wider scope of abilities. As I have written elsewhere, “research and development should challenge traditional paradigms and research processes, interrogate their ableist underpinnings, and upend practices that perpetuate the invalidation of the voices of people with disabilities. Moreover, pathways into careers in science, technology, engineering, and math for people with disabilities need to be thoughtfully and purposively constructed so that their functions on research teams can be as varied as the heterogenous disability experience.” (2018, 138).



The phrase Nothing About Us Without Us appears alongside a stylized drawing of several people clasp hands. Below the image it reads "Based on slogan popularized by South African disability rights and youth activists." [Source](#).

The global disability rights community has long been mobilized by the phrase, "Nothing About Us Without Us." This phrase should not just be applied to social, political, and cultural dimensions, but to the development of the technologies as well. Our material world, the technologies we make and use, shape and are shaped by the values we embed in them. Who has a seat at the table in the design of these technologies bears crucial consequences in how, why, and when they are used. People with disabilities should not be tokenized in the design process – asked only for approval on whether a system or design is socially valid. The most impacted should be deciding what questions researchers seek to answer in the first place.

Thank you.

Rebecca.Monteleone@UToledo.Edu

@BeccaMonteleone

RebeccaMonteleone.com

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