Everyday Experts: Transforming Research and Design Practices for Disability

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First, I'd like to thank Drs. Michael and Abbas as well as the entire ISTAS team for bringing us all together this week to discuss these important but often unrecognized topics. As a brief image description for those who may not be able to see me as well as you'd like, I am a white woman with short dark hair and glasses. I am in my home office with a bookshelf and artwork hanging behind me.

Today, I will be discussing the critical importance of lived experience in the design and deployment of technologies for disability. I define disability technology and design for disability in an intentionally vague way – historically, disabled experiences have been relegated to medical technologies or specialized assistive tech, both of which I will discuss today, but this in some way implies that disabled people are not users of everyday technologies or public infrastructure – widening the already existing social gulf between disabled and nondisabled people. Design for disability should not be considered only biomedical tech, as this casts disabled people as purely non-agential patients. In fact, one of the recommendations I hope to leave you with, as designers and engineers, is flexibility and humility in your design practices to recognize the solution to a disability-centric problem may not only not be a medical or assistive technology, but may not be a technological innovation at all. I urge us all to not only get out of our disciplinary silos, but out of techno-optimistic mindsets entirely.

A very brief note on language – the histories of the language used to discuss disability have been fraught, particularly in the United States. I will use identify first language throughout this presentation – disabled people as opposed to people with disabilities - to signal my alignment with disability theorists, advocates and activists who believe person-first language may further alienate disabled people by

suggesting that their humanity is in spite of their disability. As Kathleen Downes wrote in 2014 in her wonderful blog advocating for identity-first language, "My disability is infused in my person, not an ugly outgrowth that must remain next to my person."

I will also be using the term "bodymind" as made popular in disability studies by Sami Schalk and Margaret Price, among others. This term suggests that the body and the mind are not two separate objects, but a single imbricated unit. It is a term that is especially salient in work looking at biomedical interventions, which often force an arbitrary distinction between the thinking self and the embodied self. The use of a term like this can force us to interrogate where those lines get drawn.

Disability, too, is a term that requires some additional consideration. While many of you are likely familiar with a definition of disability – or disabling conditions – that focuses on biological or physiological deficit, when I use the term disability, I am not referring to a list of conditions with diagnosable or clinically detectable conditions, "but a contextual and contingent state of being determined by biological, social, political, and cultural conditions." Disability is determined by its counterpart, ability, which itself is contingent on a given social, political, and physical context. This is not to say that biological and physiological differences do not exist, of course they do, but to highlight that the binary between disabled/nondisabled (healthy/unhealthy or well/unwell)) is not inherent or predetermined (Monteleone, 2020, 2). This definition situates disability not inherently in the bodymind but at the interface between the bodymind and an environment designed for able-bodied, neurotypical participation, the precise place where engineers intervene. It is particularly salient when designing for disability expressly because of the tendency to design metrics for success that are reliant on a bodymind crossing the constructed threshold between disabled and able in functional ability or social/political participation.

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. Drawing on examples from media, disability activism, and my own empirical work on individual experiences of biomedical technologies, what I want to do today is present an argument that current practices in engineering and design are insufficient and in fact oppressive when they fail to acknowledge the embodied and experiential expertise of disabled people. I will conclude by providing a series of provocations for transforming engineering culture and practice.

While my presentation will not center directly on public interest technologies, I do want to raise critical questions about the construction of "publics" and who, crucially, is often left out of those constructions. As I have written elsewhere (Monteleone, 2020), the pathologizing of disability – and by extension, disabled experiences – not only creates an epistemic regime in which medical professionals, scientific experts, and technologists claim authority over disabled lives, but a political and social system in which one's access to full citizenship is contingent on the approximation of able-bodiedness and able-mindedness. Devlin and Pothier dub this "dis-citizenship," which informs not only civic participation but individual agency to accept or reject technological innovations. As Alison Kafer writes, "understanding technology as something that everyone is equally empowered to accept or reject, as something that operates within the privatized realm of individualized choice, obscures complex histories, webs, and attachments of technoscience."

Epistemic Injustice at the Core of Oppressive, Exclusionary, or Simply Bad Design

People are experts of their own bodyminds. It is generally taken for granted that person-centered design practices produce more reliably usable results, as does the diversification of engineering as a profession. By taking the experiences, desires, and needs of disabled people seriously,

we create better technologies, health infrastructure, social systems, and political structures. However, despite on-going dialogues among engineers about person-centered research and practice, disabled people still remain conspicuously absent from technology design. More often than not represented by flat personas that reduce disabled people to a list of functional impairments, the resulting technologies often embed stereotypes about disability in their design.

Disability Dongles and Unusable Tech

Image 1: Image of man from the waist down walking across a boardwalk. He has a robotic exoskeleton attached to his legs and walks using two blue canes

One way to think about this is through what Liz Jackson calls the "disability dongle." This refers to a "a well-intended elegant, yet useless solution to a problem we never knew we had. Disability Dongles are most often conceived of and created in design schools and at IDEO." These kinds of designs are often high-tech, outrageously expensive, and rarely move beyond the prototyping stage. They often receive an astounding amount of press coverage – often because they're designed by students who have never encountered a member of the disabled end-user category. Whether a flashy new of exoskeleton for quadriplegia, wearable sensors embedded in gloves intended to translate sign language, or an untenably heavy and expensive stair-climbing powerchair, disabled scholars, activists, and community leaders have pushed back against the high tech appeal of these sleek innovations.

The stakes are not simply device abandonment, these voices argue, but the misrepresentation, belittling, or dismissal of disabled experiences. Sociologist Jenny Davis, quoted in a 2013 article by Jathan Sadowski, states exoskeletons may in fact represent "a step backward, a move toward the further denigration of physically impaired bodies…[implying] that walking, rather than wheeling, is necessarily the preferable state of mobility."

Image 2: Image of man sitting in front of laptop with one fist raised in the air. He is wearing a leather glove that has been augmented with sensors on his fingers, wrist and forearm

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Of American sign language translating gloves, many of the most high-profile designs earn hearing design students scholarships and accolades according to an Atlantic article Michael Erard. But Deaf linguists and others have criticized them for reducing the complexities of sign language (which includes not only hand gestures, but facial expressions, proximity of hands to the body, mouth movements and regional dialects). This design also firmly positions the burden of translation onto the Deaf person – it is not the hearing person who must wear the unwieldy and unreliable gloves, but the signer, and in fact these gloves do nothing to increase the signers access to spoken language. As Deaf scholar Rachel Kolb states in this same article, "The concept of the gloves is to render ASL intelligible to hearing people who don't know how to sign, but this misses and utterly overlooks so many of the communication difficulties and frustrations that Deaf people can already face." More to the point, Julie Hochgesang, assistant professor of linguistics at Gallaudet University (the US's oldest Deaf university) states, "Why bother with silly gloves when we still need to take care of the basic human-rights issues?" Both statements reveal a lack of cultural and social embeddedness in these design processes.

Image 3: 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.

Perhaps no disability dongle has received as much ire as the oft-prototyped (and almost never commercially available) stair-climbing wheelchair. As s.e. smith, a disabled journalist, wrote for Vox in 2019, this particular disability dongle captures the exploitative nature of the narrative around exclusive design, noting "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 (again, often with no insight from disabled people themselves) are cast as

saviors to a despairing disabled public. This solution also does not take into account that powerchairs –

the kind that don't climb stairs – often cost upwards of $30,000, with insurance coverage being no

guarantee in the US. Nor does it account for the fact that 20% of disabled Americans are living at or

below the poverty line and don't have funds to augment insurance coverage. The Scewo Bro, seen in the

image here, costs about $40,000 USD without seat and back cushions, an adjustable head-support,

lateral leg support, or customized sizing (so making the assumption that all wheelchair users fit within

standard body types). From promotional images, it also does not appear to have any kind of harness or

buckle system in the standard design. It appears, for all purposes, to be a wheelchair designed by and

for nondisabled people. Do these large and unwieldy designs fit on public transportation? Can they stay

charged throughout the day or does a person need to stay close to home? Are they waterproof if one

gets caught out in the rain? None of these questions have obvious answers from either the media

coverage or the manufacturer site itself.

Image 4: Screenshot of Twitter. @Nivhcara_Yahel subtweets @JaiVirdi. JaiVirdi's tweet reads "Stop teaching design students to build prototypes of useless disability technology. #DisabilityDongle" @Nivchara_Yahel writes "Designers who create wheelchairs that climb stairs misunderstand the problem. The problem is the stairs, not the wheelchair. A lot of people don't use wheelchairs, but also can't climb stairs. By mistaking the problem, designers leave us out. #DisabilityDongle #HellaInaccessible

Such tech also does not consider repairs and replacement parts – specialist tech that needs to

be sent away for expensive specialist repairs means users are left without mobility and assistive devices

for long stretches of time. 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

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another stair-climbing chair, "Designers who create wheelchairs that climb stairs misunderstand the problem. The problem is the stairs, not the wheelchair."

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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.

The result of design that is not attentive to the lived expertise of its intended end users is often simply unusable tech. We can assistive technologies as an example. While ostensibly designed with specific disabled communities in mind – abandonment rates have been notoriously high. Some of the oldest data available, from a 1993 Phillips and Zhao article suggests that approximately one-third of assistive tech devices are abandoned. The primary reasons they cite are lack of consideration of user opinion in selection, ease device procurement, poor device performance, and change in user needs and priorities. In other words, users are often left out of decisions regarding the device, which then does not perform as expected or desired. While there has not been such a comprehensive survey conducted since, scholarship and anecdotal evidence suggests not much has changed in the intervening time.

Image 5: A circuit board, battery, continuous glucose monitor, insulin pump, and Carelink USB on a table. They are all labeled in purple text. Attribution to @DanaMLewis #OpenAPS

At its core, there appears to be a fundamental disconnect between disabled people and the people who create and design the technologies they use. I saw this disconnect acutely while conducting research with Type 1 diabetics who have hacked their devices in order to customize and automate insulin regulation. Here, a disdain for manufacturers of insulin pumps, continuous glucose monitors, and accessories was not just rooted in frustration with ineffective design (although that was certainly present), but in a fundamental distrust in a company that does not center disabled perspectives. As one of my informants said to me "My motivation and the motivation of people in the DIY community is parallel. My motivation and the motivation of Dexcom [manufacturer of a popular continuous glucose monitor] are not…"

Another tension that arose was the presupposition from designers and engineers that the problems a person encountered when using tech for disability was because of embodied disability and not discriminatory infrastructure or inattentive design. As another informant stated, when discussing his reasons for moving away from FDA approved devices for his young daughter's TID, "I think, arguably the most important ingredient in these communities is an unwillingness or just a recognition that so much of this is the built world. These are human choices that humans made, and it's changeable…The disease state, maybe not, but everything that we build around it is. We made it this way and it doesn't have to be this way. It could be a different way."

So, What is the Different Way?

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At its simplest, meaningful inclusion of disabled perspectives in design and engineering is important because disabled people can identify barriers, opportunities, and desires that able-bodied/able-minded people cannot. Secondly, if you don't include these perspectives, you may be

inadvertently contributing to ableist and oppressive social and material structures – which is of course, the opposite of the call for tech in the public interest.

To return to the title of this talk, "Everyday Experts," the knowledge a person has is intrinsically linked to where they are socially located. Sandra Harding articulates this with her standpoint theory, Donna Haraway with her partial objectivity, Rosemarie Garland Thomson with her misfit theory – the latter of which specifically applies these ideas to disabled bodyminds. Simply put, if you experience oppressive infrastructures, you know more about it than someone who does not.

A simple, and perhaps obvious example: If you ambulate using two legs and climb stairs easily, I can guarantee you are less aware of curb cuts, ramps and step ups than someone using a mobility device.

A secondary piece of this idea is that disabled people are unacknowledged innovators by mere virtue of the fact they exist in a world that was not made for them. As Michelle Yergeau writes in a piece condemning the ableistic paradigms that drive "hackathons," "We are the movers, not the moved-upon. We are the ones who should be hacking spaces and oppressive social systems; we should not have our bodies and our brains hacked upon by non-disabled people." (2014, para 27). Invoking Yergeau's idea, which they call "criptastic hacking" Aimi Hamraie and Kelly Fritsch (2019) write of "crip technoscience" and "crip technology" as explicitly taking up disabled experiences in design practices, defining it as "a field of relations, knowledges, and practices that enables the flourishing of crip ways of producing and engaging the material world" (4). Ultimately, they celebrate where this expertise is already valued – in the adaptation of off-the-shelf technologies or knowledge exchanges in informal communities.

So how do we formalize this knowledge? How do we remove the systemic barriers that prevent disabled people from becoming engineers? How do we transform our design practices to recognize diverse forms of expertise, not in tokenistic ways or too far downstream to have any meaningful impact,

but from the beginning how do we center disabled perspectives – including the perspectives of

neurodivergent people, of people who communicate nonverbally, of people who experience mental

illness? How do we dismantle gatekeeping apparatuses that have prevented people with intellectual

disabilities from participating in the decisions that impact their lives? I believe we already have the tools

and models we need to make this paradigmatic shift.

Image 6: A black shirtless man gestures toward the camera with his hands. Text above him reads "All bodies are unique and essential. All bodies have strengths and needs that must be met. We are powerful, not despite the complexities of our bodies, but because of them. We move together, with no body left behind. This is Disability Justice

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Most importantly, how do we design with enough humility to recognize that the expertise we do

have – as engineers, as academics – might not be the right expertise at all? To answer this question, I

turn to the 10 principles of disability justice. Created by the artist-activist collective Sins Invalid, these

principles articulate a pathway to collective liberation, built on a framework that understands that:

- "All bodies are unique and essential.

- All bodies have strengths and needs that must be met.

- We are powerful, not despite the complexities of our bodies, but because of them.

- We move together, with no body left behind."

In those 10 principles lies the answer to my question. Disability Justice principle #2 states: "We must be

led by those who know the most about these systems and how they work." I urge you all here to take

that to heart in the pursuit of not only tech that is ethical, tech that is in the public interest, but tech

that is just. I'm going to end there, and I look forward to having conversations with all of you about how

to move these ideas into practice. Thank you.