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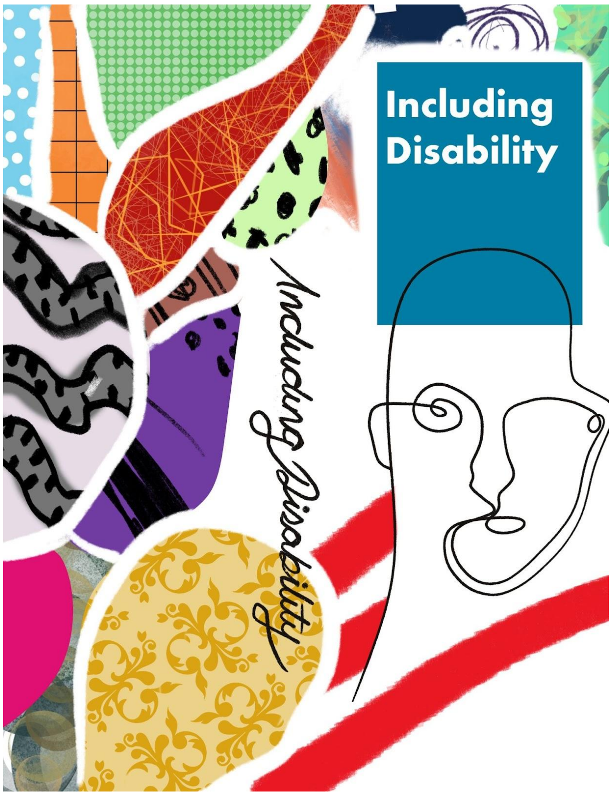

Image Description: A *collage of bright abstract patterns with colours of red, purple, green, and gold frame a hand drawn face with looping black lines. Above the face reads the title of the Journal Including Disability. This is also handwritten in beautiful cursive vertically at the centre of the page, overlapping with the colourful cutouts*

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How To Get A Story Wrong: Technoableism, Simulation, and Cyborg Resistance

Ashley Shew (she/her), Virginia Tech

Tropes about disability, stereotyped views and biased visions of what disabled life is, often occupy - haunt, maybe - the ways in which technologies related to disability are designed, marketed, and shared. Technology is then taken as a redemptive power for that which demanded an answer or solution or some means of address. There are two errors in our traditional narratives -- (1) we get stories about technology wrong, and (2) we get stories about disability wrong, both of these because of how we talk about disability technology. I'm interested in telling better stories about technology and disability, some of these in the service of better technology, better design -- but really in service of disability community and disabled flourishing.

Many of us end up, as disabled people, participating (often without our consent) in stories, in collective imaginings, that do a disservice to our communities, and our agency in creation/design, our desires both in community and in desired technologies, and our participation both within design spaces and in the larger world. We too often become fodder in someone's do-gooder folder and serve narratives that elevate nondisabled designers as experts and heroes for taking on the challenge we disabled people present.

Part of the problem in how we talk about disability is always sending it back to the individual -- this has been instantiated in law and process, people talking of "individuals with disabilities" or worse "persons" (which harkens to missing persons or reports of crime, and continues to emphasize our separateness from each other, we are not even people in this term). It lets people think we are not a collective of any sort, lets them think we don't have culture or community or relationship with each other because of disability. Individualization de-politicizes disability by keeping us separated.

For this paper, I will first share with you what we take to be the wrong stories out there about disability - narrative arcs we've inherited from tropes through various media as well as highlight the dangers of disability simulation to address these. Next, I'll talk about better stories, more authentic narratives we might give about technology and about disability. Third, I'll talk about social responsibility in the context of disability narrative, before ending by talking about cyborg-cripborg-disability expertise and knowledge with a reflection on cyborg expertise during the COVID-19 pandemic.

The Wrong Stories

Life as a Disabled Person is often lived against the backdrop of media tropes. People assume things about you. What people often imagine about you is framed by social, cultural, and religious tropes - these are reflected in media.[9] What people think you need is often framed by these tropes. The technologies we develop - and how we talk about those technologies - reflect our stereotypes.

What I offer here is not an exhaustive list, but simply a few narrative tropes we find most common in contemporary media, particularly with regard to technology. These tropes about disability - the way disability is often framed and shared - present limited ways to be in the world, in all cases disability as brokenness or aberration, something that is wrong. Disability, in this way, warrants scrutiny, policing, documentation, dismissal, intervention, and commentary. This way of approaching disability comes directly from tropey ways of thinking about disability.

But here are the five tropes that we think most people will recognize:

1. Pitiable Freaks
2. Moochers and fakers
3. Bitter Cripples
4. Shameful Sinners

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[9] Riffing on the Peggy McIntosh's Invisible Knapsack, Damien Williams has an excellent list of questions to bring this idea forward -- for groups beyond just disabled people. How we are perceived determines both how people interact with us and what technologies they build - and biases therein (Williams 2021).

5. Inspirational Overcomers

These tropes are general categories and play out differently based on various facets of identity and social context. As a white woman on a prosthetic leg with a gait that has improved over the years, I have a body that is often read as this last one, “inspirational overcomers” -- that I am overcoming my disability in some way through tech. Of course, none of us stays in one frame, and different people read us differently: to some, I am a pitiable freak with a broken body that is perhaps medically interesting, while others might inquire what I did to cause my amputation, in other words: what shameful sin made me deserve this body?

Lynn Manning in “The Magic Wand” describes whipping out his white cane, indicating his blindness, and how that changes the biases and perceptions around him from stereotyping him as a tall black man who might be good at basketball into a blind black man who surely can pound the keys of a piano with flair (2009). Here there are specific tropes about blind black men at play. So none of these tropes are universal, but they speak to how people try to interpret and understand and infer things about us -- especially as they think about design for disability. Brokenness calls out for a fix, but only for those who “really” “deserve” it.

I often show people these tropes through viral image-driven memes, characters in movies, and typical news stories. For instance, the pitiable freaks trope gets played out during U.S. prom season when media stories cover the heroism of high schoolers who ask disabled classmates to prom. We also see it in memes that ask you to “like and share” to show your respect for the nondisabled hero who… interacted with a disabled person, who is viewed as a pitiable object. We see it also in things like the infamous “I Am Autism” commercials put out by the hate group Autism Speaks, where they fundraise by first depicting autism as a sinister force in the world, as something that breaks up homes and families, that causes nothing but terrible fates for autistic people and those around them. This plays out in a lot of bad ways to fundraise, and has been part of the longstanding critique of the Muscular Dystrophy Association from former poster kids like "Jerry's Orphans" who opposed the Jerry Lewis MDA Telethons that aired for decades (Luterman 2020).

We see the moochers and fakers trope in a lot of coverage about disabled people cheating and lying to get disability benefits or some accommodations that people don't think they deserve. Almost every story in media about someone using the Americans with Disabilities Act to sue for their right to access a service or space reinforces the trope of moochers and fakers where disabled people are depicted as harassing a business or trying to bilk the system. This trope is so common that many disabled people have to surmount incredible obstacles to call themselves disabled and have to work much harder to be properly documented. I have friends who won't use the disability parking that they need because they are afraid of strangers yelling at them or attacking them for its use - and have been yelled at for using it because they don't look disabled. We see this trope not only in almost every story about ADA lawsuits, we see it in meme generated like Snarky Wonka where someone has superimposed the text "Bless Your Heart… Trying to Get Disability Benefits. I Don't Think Lazy Is A Disability." It's actually really hard to get disability benefits – made so because of the assumption that people are looking to cheat the system, and people seeking disability benefits and accommodation are often treated like moochers. Most people are denied disability benefits when they apply and have to make multiple attempts. Cheating in this system is actually very low, but these assumptions and this trope often keep people from getting what they need to work, participate, or survive.

Bitter cripples is easy to point to with characters like Lt. Dan in Forrest Gump and Captain Hook in Peter Pan. One can ask: does the character have a hand amputation or a visible facial scar or difference? They might be the surprise villain by the end of the novel or play. It’s also assumed that disabled people who are cranky are cranky *because* they are disabled. It prevents us from properly complaining about lack of access or inclusion (since we’ll be dismissed as bitter), and the trope lets nondisabled people off the hook from listening to what might be our justified complaints about the ableism we encounter.

Shameful sinners is a long-running trope. Sometimes the sin is on the part of the mother or the disabled person, or a disability can be seen as a “challenge” to transform thinking. We see this trope play out in a lot of coverage of health and wellness where people are blamed for their disabilities or conditions and denied proper access and care. I think here of how particular types of cancer are depicted (such that, if you get a cancer diagnosis, people want to know what you did to get cancer) and how AIDS was once (and in some communities still is) depicted. The now-debunked refrigerator theory of autism blamed the mom for being too cold to her children and thus turning them autistic: it was her sin played out in her child.

After these first four tropes, the last one will seem less awful, but it’s really not, and it’s often embedded in the narratives I’m interested in. Inspirational overcomers is a trope discussed a lot in conversations about “inspiration porn” in the disability community. This trope is seen in a million memes of amputees on running blades and other athletic-looking disabled people with the words “the only disability in life is a bad attitude.”

All of these tropes imply that, to be good disabled people we have to be fighting against our bodies or minds in some way, disown our collective or community identities (to always be individuals), make ourselves objects for other people. Inspiration porn indeed makes disabled people into objects to inspire others. Other disability tropes are used to motivate shame, create pity, justify policing, and more.

We should be concerned not just about these tropes but about how they play out, get represented, and become part of our social scripts. We also need to beware that white disabled stories, especially of the inspiration porn variety, get a lot more air time. Sami Schalk and Vilissa Thompson have written about white privilege around white disabled critiques of inspiration porn (Schalk 2021 and Thompson 2016). Thompson writes:

> I ardently despise inspiration porn, but as an advocate who focuses on the achievements and experiences of disabled Black girls and women (and other disabled girls and women of color), I do not have the "luxury" of picking and choosing stories that depict us in a positive, non-inspirational light. Why is that? Because our stories do not get the same or fair amount of spotlight and recognition as the ones that feature White disabled people. (2016)

Schalk calls for an analysis of inspiration porn that takes into account cultural norms and racial dynamics and rhetoric that shape how these stories are produced and received (2021).

There are downsides for disabled people in being cast as inspiration porn, even though it seems like a good trope after you've seen the other options. Disability technologies are often part of this story: that people find the right technologies, guided by humanitarian technologists and therapists, to properly overcome the circumstances of our bodies or minds. This sets out a goal for science and medicine, and also for individuals. But why is this a bad thing?

As Stella Young puts it in the best TED talk,

> And that quote, "The only disability in life is a bad attitude," the reason that that's bullshit is because it's just not true, because of the social model of disability. No amount of smiling at a flight of stairs has ever made it turn into a ramp. Never. Smiling at a television screen isn't going to make closed captions appear for people who are deaf. No amount of standing in the middle of a bookshop and radiating a positive attitude is going to turn all those books into braille. It's just not going to happen. (Young 2014)

The "brave overcomer" trope, used in inspiration porn, is harmful. First, it treats us as exceptional individuals, rather than as community members of an underrepresented minority who may need access and accommodations and structural change, rather than gadgets to help us individually function. Second, the trope asks us to live for other people - the goal becomes about being seen properly in this role, about performance. Third, inspiration porn works against inclusive design and disability rights. **We shouldn't have to be at our best to be**

allowed to participate. Fourth, it exceptionalizes, rather than normalizes, disability as a facet of the human experience. It exaggerates how different we are. And, it suggests that we have to do this fighting thing instead of setting people up for adaptation or creativity in thinking about participating in various things. This frame can be quite annoying too -- when disabled people doing basic things in public are lauded for merely existing in public.

So, when we have these tropes about disability, and then people go off to design things imagining our bodies or minds, they still see us as fundamentally deficient -- not just people who are looking for some good tools to adapt to a hostile world, or as people who might have our own ideas about what we want (see Clare 2017 on "grappling with cure").

Here are just a few headlines -- of the type you see all the time, and you can also just search "technology" and "disability" in any news database for a list of examples –

> "The Tech Giving People Power to Deal With Disability" - BBC News
> "How Technology Will Change the Lives of People with Disabilities" - Forbes
> "First Prosthetic Limb Designed for Women: 'I Feel Liberated'" - BBC Two
> "Robotic Exoskeletons Are Here - and they are Changing Lives" - PopSci

Two notes about these headlines:

1. The stories disabled people actually tell about these technologies are VERY different than the news coverage, but often if the objects of the design (the disabled people) are interviewed at all, there's a twist to the coverage. In this BBC Two story, the interviewee arm amputee Nicky Ashwell talks about using her new - and this is its real name - bebionic arm for various tasks, why she didn't use a prosthetic arm for a while, and what she can do with it (Derbyshire 2015). This quote "I feel liberated" is a weird choice in the context of the interview. The quote "I feel liberated" is about riding a bicycle (which is easier with the arm). What is it like to ride a bicycle, for any hecking person? Probably liberating, wind in your hair sort of situation. Of course, this interview was unique because they let the disabled person talk, though she was accompanied by a bebionic representative in this story.

Oftentimes coverage centers the voices of nondisabled technologists, designers, and even family members, rather than disabled people.

2. Most of these stories leave out the context -- prosthetic arms adopted to avoid being stared at or exoskeleton development excitement because built infrastructure continues to suck, 30 years post-ADA. Bodies are taken as the problems in both these situations - normalize or enhance bodies such that our infrastructure worries vanish (they won't).

Disability Simulation

The usual response to hearing about these tropes and news coverage is to "engage" in "awareness" - so that people can see for themselves the experience of disability. A primary example of awareness gone wrong is Disability Simulation.

Disability Simulation is a practice where people "spend a day in your shoes" -- with activities that have them perform tasks blindfolded "to find out what it's like to be blind," or to try to use a wheelchair to get around, suits to simulate old age (the use of these are on the rise), or even using VR to "see" through another's eyes. These practices are actually quite bad when you look at the sociological evidence: the outcomes aren't as expected -- and the objections here are three-fold.

1. Disability simulations actually lead to negative perceptions about the competence of disabled people. Participants are experiencing what the first day of a newly acquired disability might feel like, and therefore don't get the experience of adapting and learning (and coming to see disabled people as competent). It emphasizes the deficiency. (Nario-Redmond et al. 2017, Silverman 2015, Silverman et al. 2015)
2. Disability simulations make nondisabled people think they know what it's like - such that they don't have to interact with disabled people to hear about our experiences in order to design. What is salient in the experience for a nondisabled person - say, how hard it is to push a manual wheelchair up a curb cut - might actually not be a focal part of the experience for someone who uses a wheelchair to get around all the time and has the right arm strength and relevant embodied know-how. (Ladau 2014)
3. Disability simulations homogenize the experience of disability. Most of us have more than one, or will acquire more sooner as we age. Just using a wheelchair might tell you very little about how someone experiences their disability - or the variety of ways their disabilities impact them. What they take as a focal concern might not be the same even as someone with the same disability. (Ladau 2014, Silverman 2015)

"Design for disability" from these experiences takes disability as the object - with the feeling from nondisabled designers that they have properly learned about their job from their own simulation of the experience. The simulation is misleading and does a disservice to disabled people - so design that flows from this is highly problematic. Engaging in disability design should be, in the framing of Liz Jackson "design with disability" (2018) - with, ideally, team members who have the relevant disability and are part of communities that matter to the research. And this is where exoskeleton complaints easily arise: so often made with military funding with disability as the humanitarian cover for what is a project which has an end not in actually being worn by disabled people as their primary means of mobility (they might be a useful tool sometimes), but in military might.

What arises in the context of disability simulation, "life-changing" rhetoric in news stories about disability technologies, as well as tropey depictions that come from many of our cultural and media touchstones is ableism, deeply entrenched. Ableism isn't just individual bias. Fiona Kumari Campbell explains: "...ableism is deeply-seeded at the level of epistemological systems of life, personhood, power, and liveability. Ableism is not just a matter of ignorance or negative attitudes toward people with disabilities; it is a trajectory of perfection, a deep way of thinking about bodies, wholeness, permeability and how certain clusters of people are en-abled via valued entitlements" (Campbell 2009, page 5).

Technoableism is this word I coined to describe a phenomenon that a lot of disability scholars interested in tech are describing right now (Shew 2020). Disabled people are often objects for design - to be designed around, a fun design challenge - in technoableism. Technoableism steamrolls disabled voices and agency, and it elevates nondisabled helpers. Even when there's talk about empowerment, the underlying assumption is that disabled people need to be empowered by technologies and by helpers, these humanitarian engineers and noble Accessible Tech specialists -- rather than addressing systemic issues that lead to disabled people having less power, agency, and choice. Individuals are taken as the problem, the medical model unbroken, even outside the medical system.

Technoableism, as a subtype of ableism, involves the emotions/attitudes, actions/practices, and beliefs/stereotypes that Michele Nario-Redmond describes in her book Ableism (2019), but it is set within the context of a belief in the good power of technology and ideas about progress and who is fit for life. We see, in praise and promise of bodies in technology, the idea that disabled is a bad thing to be, that one must be altered to be worthy.

Technoableism is seen in marketing about disability technologies. Disabled people are told technologies will change our lives, never just incremental improvement. It's seen in the dearth of stories about disabled designers. Disabled people are always the recipients in these stories, those helped but never helpers. It is seen in "feel-good" news about technologies for good. Disabled people are often talked about in these stories without being interviewed. So, ableism is bias against disabled people or in favor of nondisabled ways of being. Ableism is part of how we make judgements and value particular forms of communication, intelligence, professionalism, rigor, lifestyles, etc. It influences what we build and how we build it, how we organize our lives and societies. (It even plays into who gets counted as disabled and who does not.) It's a sauce we are all marinated in.

The Cyborg Jillian Weise expresses what technoableism does, how it lets nondisabled people take the lead in designing our tech, how this shapes what is pursued:

> They like us best with bionic arms and legs. They like us deaf with hearing aids, though they prefer cochlear implants. It would be an affront to ask the hearing to learn sign language. Instead they wish for us to lose our language, abandon our culture and consider ourselves cured. They like exoskeletons, which none of us use. They would never consider cyborg those of us with pacemakers or on dialysis, those of us kept alive by machines or made ambulatory by wheelchairs, those of us on biologics or anti-depressants. They want us shiny and metallic and in their image. (Weise 2018)

As I currently am working on a book on the topic of technoableism, I have written: "the sharper end of technoableism is that, if one cannot measure up by technological means, then there are technological-eugenical means for "dealing with" the most unfortunate cases. Prosthetic legs, Prozac, pacemakers, ostomy bags, fidget spinners, heating pads, and wheelchairs are technologies for disability just as much as gas chambers, institutional confinement, and prenatal de-selection" (Shew, forthcoming). What it means, if your body or mind cannot be redeemed by technology or if you are not interested in such redemption, is sometimes terrible.

Better Stories

So far we've told you about tropey depictions and how we are in this state where conversations about disability and technology are tainted by tropes and simulation. The stories are wrong. The sharper end of technoableism is death, dismissal, elimination, or a willful push out from disability identity in policing/documentation. The sharper hurts the most marginalized in the disability community the most. We need better stories for us all.

And, in listening to and reading from disabled people, we find those stories. We want to indicate our gratitude to Alice Wong for her work in the Disability Visibility Project that promotes disabled-led storytelling and conversations between disabled people about our experiences (2014-2021). Our current research has had us draw from DVP's resources as well as disabled memoir, poetry, blogs and vlogs, and more. This takes place against the backdrop of a public imagination that has long stereotyped disabled existence.

Three Failures of Technological Imagination

Technoableism has shaped three primary failures we find common in discourse about technology and disability. When we reify tropes about disability, we actually fail to recognize the structures in which disabled bodies operate -- this can mean commercial failure, which happened on the part of Dean Kamen’s iBot stand-up wheelchair (Watanabe 2009). Some wheelchair users loved it, but lack of understanding by the makers about medical devices meant that Medicaid, Medicare, and then private insurance plans would not cover, even partially, the cost of the iBot. I also think of the community-driven technologies that have been sucked up into wider use and how they aren’t seen as disability lifehacks anymore: straws, pre-cut veg, Snuggies, OXO kitchen tools (Jackson 2018, Jackson 2018).

You can make all the exciting technology in the world -- and make good things that people might want -- but very few people may end up with that technology if you aren’t in contact with communities who know what they are navigating when it comes to bureaucracy.

This relates to the second failure here too: infrastructure is part of what we’re navigating. An exoskeleton (Istvan 2015) only seems like a necessity when we’re not doing basic repair to our buildings and sidewalks -- and upholding a 30-year-old law like the Americans with Disabilities Act, when we aren’t renovating all homes and buildings with the expectation that disabled people should be able to visit, live, and work where everyone else is.

The perception of a technology can also make it fail (this is social infrastructure at work): so many technologies aimed at older people, even when they would be useful, have stigmas associated with them -- hearing aids, canes, medical alert buttons, and walkers. Hearing aids have a double punch: insurances won’t cover them usually (and they can be costly) and they have some stigma associated with them for some groups. And we use the less good version of crutches -- underarm crutches -- when forearm crutches are mechanically superior, put less wear and tear on your joints, and are what any crutch-related sport is played on because you can move in much more dynamic ways with them. But the stigma of long term disability - often associated with post-polio syndrome or CP - rests with the technology. Perceptions about technology play into their reception by newly disabled people.

The third point here -- the failure to imagine different ways of being as good or as freeing also becomes a moral failure when you push that belief about what is good onto the bodies of other people. My friend Mallory Kay Nelson expresses it best when she discusses all the options we really do have as amputees, more than non-amputees when it comes to how we move in the world (Nelson et al. 2019). Leg amputees can use wheelchairs, crutches, sometimes knee scooters, walkers, rollators. She talks about transmobility - the movement between different ways of moving in the world, different mobility technologies. And we can be just as good in any mode. The technology isn't what determines our goodness, the value of our lives.

When we think about cool and creative designs and see bodies as the site of possibility, we think about tentacle arms, running blades (which aren't supposed to look like meat legs), and other ways around that challenge normalization and celebrate difference. We also think of tech that defies: like spikes on wheelchair handles, brightly colored fidgets for stimming without hiding, and the crippled punk aesthetics.

The fact is that technological imagination in design spaces has not caught up with disability activism and disability studies. We see ableism in just the assumption that everyone either would benefit from or would want to walk. -- and so many stories when we make people walk. On the first day of each semester in my tech and dis class, I read an excerpt from Harriet McBryde Johnson's book Accidents of Nature (2006) about disabled kids at disabled summer camp. In the book, one camper pages through the scrap book of another camper and comments on how adults, thinking it is best, basically torture them into walking, even when its a crappy way to get around for some disabled people.

Bill Peace, blogging as the Bad Cripple, explains:

> Your typical bipedal person exposed to a barrage of misleading news stories is led to believe all paralyzed people share one goal in life -- walking. Please cue the soaring inspirational music accompanied by the brave and noble young man or woman, struggling to walk surrounded by health care professionals, computer scientists, and

> engineers who share the same ritualized ideal….The flip side of the obsession with walking is not discussed. No one wants to talk about the gritty reality people who cannot walk are forced to navigate. No one wants to think about the barriers to health care and appropriate adaptive technology…. Disability must be placed in the larger societal, historical, political, and medical context. It requires a new way of looking at disability…. (Peace, 2015)

This can be painful, especially for those around us "just trying to help," to resist their help, their designs, to hurt their feelings because they thought they were being helpers and feel it an affront to be told that help is not helpful or wanted. It's not uncommon for a newly disabled person to be sent articles and stories, like those new stories discussed earlier, about exciting new life-changing tech that will make things less miserable than they assume our newly disabled lives will be -- this flows from several tropes and their own imagining of our experiences.

Here Catherine Campbell writes about an exchange with her congenital arm amputee son Thaddeus:

> We were sitting on the couch, and he turned toward me. "I've been thinking about it," he said. "And I don't want a new hand."
> "But why?" I was devastated. All that time, research and enthusiasm. He was throwing away a chance to have a five-fingered hand? He was quiet for a moment, then started to explain his three reasons.
> First of all, he said, he didn't want to lose his sense of touch. "I don't want to lose the way things feel." This caught me off guard. I hadn't thought of how much he could physically feel at the tip of his wrist, how stifled it was under something else like plastic.
> "I can figure out how to do stuff my own way." It was true. Thaddeus had figured out how to leverage his arms, feet and neck to open jars, marker and pen caps, and even play baseball. "My brain just works different because of my hand, and I think that's a good thing… And my friends like me just the way I am," he said. If he started wearing a new hand, he explained, it would draw more attention to him — the kind he didn't want. "I don't think kids would be my friend because of me. They would just want to play with my robot hand."
> "So, is that O.K.?" he asked. "That I don't want a hand?" (Campbell 2015)

From *Staring: How We Look* (2009), in her chapter on Hands, Rosemarie Garland-Thomson writes about prosthetic arms - cosmetic arms versus hooks and more functional hands - "a mechanical hand answers the needs of its wearer" while "a cosmetic hand answer the needs of its starer" (page 129). Some disability tech is about making it more comfortable to be in public, as a reaction to people's biases and perceptions. The technology is not for the disabled person as much as nondisabled comfort.

Disabled people with apparent disabilities are approached in public by strangers and asked about technological and therapeutic choices - why aren't they using a particular technology? Why haven't they gotten therapy such that they are more palatable in public? Or, worse, told it is inappropriate to be in public for appearing the way they do without the technology that the person deems appropriate. There is a history of Ugly Laws and institutionalization that is just a hair away from these questions and perceptions. And of course the too-many-questions and too-much-unwanted-advice problems exist for disabled people with non-apparent disabilities as well.

Autistic HCI researcher Rua Mae Williams, critiquing technological interventions around autism, writes:

> Technologies for autism are dominated by metaeugenics via the logics of the interventional — these normalizing technologies seek to correct aberrant behaviors, shape normative social responses, and remediate deficits and delays. This approach seems natural and necessary from the perspective of the helping professions, guided by a conviction that their role is to deliver health and wellness — a restoration or purification via the "equation of the norm with health" (Edelman, 1974, p. 306). The logic behind such interventions is that access is conditional upon whether the body is 'includeable' or not (Titchkosky, 2011). The interventional approach is so naturalized that to not intervene is regarded as synonymous with causing harm. (Williams 2019)

Here they point clearly to the logic guiding interventional approaches as metaeugenics. Especially in the absence of community will or interest or guidance, these approaches work to devalue disabled experience/voice/choice/ideas – and disabled life, which becomes always seen as inferior and conditional upon the goodness of others in whether we should be allowed to be at all.

Jaipreet Virdi, a deaf historian, talking about her book Hearing Happiness (2020), explains the problem with the rhetoric we, the objects of design, feel.

> The problem with this rhetoric [about curing deafness, as we have seen over and over in history with various hearing technologies] is that it constantly promotes the idea

> that deafness is something that needs to be fixed, whether through medicine or technology. In all of these, there lies the idea that you have to fix it, have to be cured, rather than just accepting it. And that becomes problematic. I think this does something to you, and it makes deafness constantly stigmatized. It also makes it difficult for deaf and hard of hearing people to advocate for themselves. (Virdi, as quoted in interview with Nursing Clio, Shew 2020)

It is harder to advocate within the context of aggressive audism and ableism that makes assumptions about what deaf and disabled people want/need and what technologies are right, writ large. So, we're seeing these stories that got it wrong have this oversized impact in disability design spaces, in ways that do material harm and reify bias.

So what does social responsibility look like as we respect and rewrite the story of technology and disability. These are messages I want to communicate to designers, therapists, and helping helpers who are trying to get it right.

Social Responsibility

Social responsibility in this context means making space for disabled people to lead, and really listening to the disability community, recognizing the larger context in which a technology will be deployed. Recent proud nondisabled announcements heralding a new drug for achondroplasia and announcing the Spectrum 10K database of autistic genetics have shown that we have a lot to do to grow into better coverage and recognition of expertise here – to demonstrate social responsibility in the area of technology and disability.

Disabled people need to be held up and appreciated as experts when you are using their know-how, contextual knowledge, and community knowledge. It's far past time to pay your disabled consultants and collaborators, and give them credit when and where it's due! Using disabled and expecting us to be grateful is all too common. Respecting us also means citing us, crediting us, acknowledging us, recruiting us, and changing norms in your field to clear space for our existence.

- Don’t exploit your disabled friends and neighbors. - don’t exploit your more marginalized friends and neighbors: this applies to disabled people of relative privilege too.
- Recognize the importance of disabled experts engaged with disability communities. We learn from each other, and a weird wrinkle of disability community can often be that single-disability organizations and groups end up trampling on more marginalized members of their community or disabled people from other categories of disability. I think here particularly of lateral ableism in disability groups. Cross-disability community with intersectional work is important here.

Make sure disabled voices are centered in coverage about any project you are working on where it concerns disability.

This advice - about listening to disabled people - applies to all sorts of technologies. And here’s what a lot of people with what they take as cool projects don’t want to hear: There will be some projects you should not do. In some cases, this will mean that you should make the space and champion others who are appropriate for this work. It may also mean abandoning a project or trajectory in research altogether.

This is related to: you should be promoting, recruiting, retaining disabled people in your professional groups. Making us welcome. This may mean changing a lot about your current practice and resisting certain practices you have held dear around communication and professional norms.

And last: using humility, rather than empathy, when approaching a project around disability. You may not have the story right -- this is true even for individual disabled people, internalized and lateral ableism are real - so listening to each other, to disabled people in community, is essential. Empathy gets the story wrong here.

The way systems are rolling out to monitor and control people imagined as always-patients in ways that limit and curtail our freedom from interference and to control our own lives. Movements around the use of fitbit data, step counting, medical data like information from pacemakers and diabetic devices, and even disabled people's use of social media becomes ways to sort and control us. Listening to disabled people -- and, note, not their parents or caretakers or other proxy -- is really important to doing right by disabled people.

Hanna Herdegen as part of our grant work together has talked about five new frames from disability-led narratives that might help us think about what responsible approaches to disability design narrative might look like -- these are the stories disabled people are actually telling, and center disabled creativity, knowledge, action, and choice. Herdegen lays out these counternarratives (which are not meant to be exhaustive):

> Counternarrative One: Disabled People as Technology Users
>
> Disabled people are not passive recipients of technology. They are an active and diverse user group who face particular restrictions—not because of their disabilities, but because of technologists' failure to accurately imagine their lives and needs. Disabled technology users often must respond creatively to imperfect and ill-fitting devices while at the same time resisting the ableist narratives about disabled technology use produced both by technologists and by the general public.
>
> Counternarrative Two: Technology as Freedom
>
> Like any other user group, disabled people use technology to navigate the world, to accomplish tasks, and to interact with their environment. Under certain circumstances, disabled people can use technology to provide themselves with certain freedoms: the freedom of movement, of expression, of choice, as well as freedom from hunger, from pain, from fatigue.
>
> Counternarrative Three: Resisting Technology (engage the slogan "Piss on Pity")
>
> It is important to recognize that not all technologies have positive connotations for disabled users—and that technologies that are thought of positively by some disabled people are not thought of positively by others.
>
> Disabled people resist technologies and the inaccurate narratives surrounding disabled technology use, both individually and collectively.

> Counternarrative Four : Technological Ambiguity
>
> Things that we have positive relationships with, like cell phones or wheelchairs or microwaves, may continue to exist in this positive space in our minds until they start to break down. Sometimes, it is only when things break down that we even begin to notice that they are there in the first place, or to understand how important they are to us. Other times, technological breakdown reveals deeper patterns at work, like systemic discrimination or a lack of resources.
>
> If technological breakdown continues to happen—on either the level of the individual technology or on the level of technological systems, our relationship with a technology may become ambiguous.
>
> Counternarrative Five: Crip Technicians
>
> In addition to being users of technology, disabled people are also designers and technicians. This can be because they are employed or trained as an engineer or designer. But this can also be because being disabled means having hands-on experience with creative use of materials. It means it is often necessary to get creative with the things you have in order to make things work.
>
> (Herdegen et al., forthcoming)

Recognizing these more complicated, contextualized narratives helps us work against tropey nonsense and sets disabled people as expert and actor (not object) when it comes to technologies and our own lives.

Conclusions: Cyborg/Cripborg/Disability Expertise

Through all these frames, an underlying theme is cyborg expertise -- we might also call this clipborg or disabled expertise. But there’s a resistance as a throughline in each of Herdegen’s counternarratives. But what about the recent access and crisis through the COVID-19 pandemic? Where does Cyborg Expertise – Disabled Expertise – fit in our continuing conversations?

Cyborgs, technologized disabled people, have long been subject to crisis, and long working for access. Alice Wong, of the Disability Visibility Project, and a proud cyborg herself, writes:

> Disabled people know what it means to be vulnerable and interdependent. We are modern-day oracles. It’s time people listened to us. Even before the coronavirus pandemic, systems have always tried to kill and oppress marginalized people. Attempts to repeal the Affordable Care Act. Human gene editing. Wildfires in

> California. Voluntary power shutoffs by PG&E. Medicaid work requirements. Public charge rule. These crises and assaults reconfirm who is considered disposable and unworthy of assistance, resources, attention, and treatment. (Wong 2020)

Early in the pandemic in the US, an anonymous collective of contingent faculty members, TAs, and staff wrote a statement about high risk categories and campus reopening. If you can remember back to two years ago, so much of the public rhetoric suggested that "high risk people" need to be careful in an individualistic mode, rather than some shared collective responsibility we all have to keep each other safe. They also cautioned against "approaches that provide exceptional and one-time accommodation" to those who are high-risk (Accessible Campus Action Alliance 2020).

They identified what was happening in the larger world as an ongoing issue of civil rights, not a one-off crisis:

> Campus re-openings are an issue of civil rights, particularly disability, racial, and gender equity. Given the disproportionate representation of COVID-19 infection and death in Black and brown communities, university policies that emphasize in-person work and teaching run the risk of compounding the impact of racial inequity. These policies also risk endangering already-marginalized members of university communities, including staff and contingent faculty who are less likely to have the option to take time away from work. As a matter of justice, equity, and ethics, we call upon university administrators and communities to value the lives of marginalized racialized and disabled people over the purported economic value of campus re-openings. (Accessible Campus Action Alliance 2020)

The move to talk about high-risk people was to individualize the pandemic. High risk is not a community. Of course, it covered over talking about disabled, chronically ill, and older people, particularly those from historically exploited and mistreated populations. Here I am thinking not only of black and indigenous people of color and the alarming death rates in some of those communities, but of institutionalized disabled people (some who are also BIPOC) in group homes, psychiatric institutions, rehabilitation hospitals, nursing homes.

As with many historical pandemics, we can and should expect more disabled people: we disabled people know about this already, could have told you. None of this is unprecedented. And in fact even a year ago disabled people organized, even as we dispersed and distanced, to expect this, to see a rise in community as we prepared for our losses too. Disability is a risk factor and result of COVID-19 - something well noted by many disabled people over this on-going time.

Samuels writes in “Six Ways of Looking at Crip Time”:

> Crip time is time travel. Disability and illness [--and here I would add pandemic and crisis, maybe--] have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings.... The medical language of illness tries to reimpose the linear, speaking in terms of the chronic, the progressive, and the terminal, of relapses and stages. But we who occupy the bodies of crip time know that we are never linear, and we rage silently—or not so silently—at the calm straightforwardness of those who live in the sheltered space of normative time. (Samuels 2017)

I think about this, the work of narrating our bodyminds while honoring them, in how we move in spaces, in how we adopt and adapt technologies (and what we choose), and in how we remake a world, forged by disabled people who know access and crisis too well, remembering, honoring, and celebrating disabled people, recognizing crip expertise, and cyborg resistance. We have to think about how disability policy and progress can shape our efforts as we confront and combat ongoing ableism, eugenics, white supremacy, and new crises.

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About the Author

Ashley Shew is an Associate Professor in Science, Technology, and Society at Virginia Tech, where she participates in the STS PhD program, the Medicine & Society minor, the Disability Studies minor, the Bioethics graduate certificate, and Integrative Graduate Education Program on Regenerative Medicine. Her current research is about disabled expertise and disability-led narratives about technologies (in contrast to the tropey stories we usually get). She's working on open educational resources on Technology & Disability with Hanna Herdegen, Damien Williams, and a team of undergraduate research assistants, made possible through NSF Grant #1750260, and she is writing a book called Technoableism to be published with Norton in 2023.

Ashley's past work has been in philosophy of technology with particular interest in technological knowledge, animal studies, and emerging technologies. She is co-editor-in-chief of Techné, the journal of the Society for Philosophy and Technology. She is sole author of Technological Knowledge and Animal Constructions (2017) and co-editor of three philosophy of technology volumes: Spaces for the Future (with Joe Pitt, 2017), Feedback Loops (with Andrew Ganar, 2020), and Reimagining Philosophy and Technology, Reinventing Ihde (with Glen Miller, 2020). She believes in cross-disciplinary, cross-disability, and public-facing scholarship: she has written for IEEE Technology & Society, Nursing Clio, Nature, the Chronicle of Higher Education, and Inside Higher Ed. She is a grateful participant with her local disability advocacy and activist community in the Disability Alliance and Caucus at Virginia Tech and the New River Valley Disability Resource Center (a CIL).