Disability Design, The Engineer's Dream: Cyborgs and How We Fail Them.

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

The largest minority group in the world is disabled people. It is a group that can be joined by anyone, at any time (Garland-Thomson, 2017). According to the CDC, 61 million Americans are disabled (CDC, 2019). Over time, technology designed to assist disabled people with daily tasks and movement has evolved from simple and rudimentary devices, to complex and powered. Great leaps have been made since the 20th century, as mobility aids have moved away from peg legs and passive wheelchairs to high tech prosthetics and motorized wheelchairs. However, these devices are often designed and created by people who are not disabled, and not necessarily with disabled people in mind.

While there are many categories and types of technology for disabled people, I will focus exclusively on mobility technology, as mobility disabilities are the most visible. I will explore how disabled people, designers of technology for disabled people, and society interact using Actor Network Theory, and whether or not non-disabled designers can create and build good technology for disabled people. To that end, I also define what "good" or well designed technology is in this context. As disability technology affects a particularly vulnerable sect of the population, extra thought and consideration must be dedicated to proper design practices for this type of technology.

Designers must focus on making technology that is user-friendly, durable, and easy to maintain. While much of the drive for innovation centers on "better, faster, stronger," this leads to short term rather than long term solutions to the chronic challenges posed to disabled people. Engineers try to promote "greater performance" while the reality is that disability is a long term problem that requires robust, long-term solutions (Kafer, 2002).

History of Mobility Aids

The first mobility aids were recorded in the 5th Century BCE in an image of the Chinese philosopher Confucius in a wheelchair. Though this chair was rudimentary, it was still intended to increase mobility. Mobility aids began developing in earnest around the 14th and 15th Century BCE, with a three wheeled walking frame in 14th century England and prosthetics and an elaborate wheelchair for King Felipe II of Spain. It took until the 18th century for the development of something we might recognize as a wheelchair, with subsequent renditions in the 19th century being made of wicker and wood. The first folding wheelchair was made in 1932, following the first electric wheelchair in 1924 ("The History of Mobility Aids," 2020).

Today there are several major types of mobility aids: mobility scooters, walkers, rollators, wheelchairs, crutches/canes, and prosthetics. Rollators use wheels on all contact points, whereas walkers do not. While these categories do not encapsulate all forms of mobility technology, and the list of examples is non-exhaustive, they give a broad description of the function and form of mobility technology as most people are quite familiar with these devices.

Today's mobility technologies go beyond the minimum definition of mobility and can allow disabled users to be quite independent, albeit if infrastructure and circumstances allow. These technologies also allow disabled people to push the limits of their mobility and independence. In particular, development of "intelligent" mobility devices in recent years provide increased independence and mobility (Mihailidis et al., 2007).

Actors and motivations

In the network of disability technology, there are three major actors: disabled people, the designers, and society. The category of "disabled people" further splits into two subcategories: the permanently disabled (those with chronic conditions or congenital disorders, the paralyzed,

and amputees) and the temporarily disabled (those recovering from injury or surgery). The designers consist of the engineers, doctors, and other people involved in designing, creating, and producing the technologies. Society refers to Western society, media, and individuals. While perceptions of disabled people vary from country to country, I will generalize Western views into one category, and focus on American views. This is only a small section of the network surrounding disabled people, and is focused not on a particular disability or disabled people, but rather the technology that disabled people use, what technology is provided to them, and how they use it and are viewed using it.

Disabled people

Disabled people are the most important actors in this network. They are the users of the technology, the ones who will buy the technology from the designers, and they are the ones that have both the most to lose and the most to gain. I will focus on the thoughts and motivations of the permanently disabled, as the temporarily disabled know that they will someday (soon) be not disabled and, as a result, are less invested in the quality of their technology and more willing to overlook shortcomings in their technology. The permanently disabled have no such luxury. They will forever and always rely on mobility technology. These technologies are so deeply ingrained in their life and identity that some refer to themselves as "cripborgs" or "cyborgs" ("Common Cyborg," 2018; Nelson et al., 2019)**.** Further, their deep familiarity with the technology leads to a better understanding than designers and nonusers could ever hope to achieve. They are "experts and designers of everyday life"(Hamraie & Fritsch, 2019).

Most cripborgs have a symbiotic relationship with their technology, an adaptable relationship where they use many different forms of technology to suit their needs, a practice

called transmobility[1]. This definition allows for the re-imagining of disabled people's bodies as "playful and mobile" rather than something to be pitied or feared (Nelson et al., 2019). Transmobility emphasizes the importance of flexibility in the use of different types of technologies. While most non-disabled people think that disabled people only use a cane, or only use a wheelchair, transmobility directly refutes this perception. Not only does transmobility support the use of various forms of mobility technology, it also supports non-traditional forms of mobility. This could mean not using mobility technology at all, using home-made technology, or modifying existing technologies to suit other mobility needs. Transmobility calls for a variety of levels of mobility and different forms and functions of mobility technologies.

The Designers

Designer, when used as a term to describe someone who creates technology, is often synonymous with "inventor." Here, designer is used in the more literal sense, one that creates and manufactures a new product style or design (*Designer Definition & Meaning - Merriam-Webster*, n.d.). The designers of disability technology attempt to create technology that bridges the gap between the abilities of disabled people and the abilities of the non disabled, in this case mobility technology. Designers are beholden not only to the users of their technology but also to the companies they work for. They can be caught between deciding what is right for the user and what the company desires or is able to support. Designers can be anyone involved in the design process or creation of the technology, but are most likely medical doctors, engineers, other medical professionals, and technical experts. These actors treat disability in the medical model: where disability is a thing or problem that can be fixed. This is opposed to the social

[1] Transmobility (noun): (1) the ability to move between various modes of mobility; use of multiple mobility methods; (2) the ability to move beyond traditional forms of movement and mobility; (3) the existence of free and disabled bodies in motion. Word derived from the prefix "trans-", meaning beyond, across, through, surpassing, transition, transport, or transcending + "mobility," meaning the ability to move or be moved freely. Antonym: Monomobile. Coined by Mallory Kay Nelson. Origins: her experience. (Nelson et al., 2019, p. 2)

model which proposes that disability results from the failure of the environment to provide appropriate resources (*Conceptual Models of Disability – PM&R KnowledgeNow*, n.d.).

Doctors and medical professionals operate under the Hippocratic oath, as well as the ethical guidelines of their particular profession and place of employment and engineers and technical experts operate under the code of ethics of their profession or field. These codes of ethics can guide, but also limit, what they do, design, and create. Further, design is a vast field that crosses with many different disciplines of engineering and technology, but general design principles remain the same.

Many designers operate under the assumption that innovation and creation require that technology become "faster, more efficient, and more durable" (Earle, 2019). This idea of "better, faster, stronger" is ubiquitous among creatives and engineers. It drives and guides innovation, which is not altogether a bad thing. Between this and the aforementioned codes of ethics, designers have a solid base of guiding principles when it comes to the development of technology. However, due to the vulnerability of the sect of the population they design for (that is disabled people), designers of disability technology must consider other factors as well.

Society

Society is isolated as its own actor in this case as it exerts pressure on the other two actors in different ways. Society also assigns value to different members, institutions, technologies, and devices. This assignment of value places pressure on these different entities to act, behave, and create in a way that conforms to societal expectations. Much of these expectations are delivered through media, both the news, social media, and entertainment.

> "Although there are no specific data showing attitude change in response to media communication, people tend to believe that the manner in which characters are portrayed

> is important. Characters presented on screen are sociocultural stereotypes designed to appeal to the majority of viewers, and reflect widely held values (albeit mostly American). It seems apparent that the repeated presentation of images in an acceptable and palatable manner will result in those images becoming a typification of everyday existence." (Dahl, 1993, para. 9)

For example, disability has been used as an archetype in literature to provide a certain amount of characterization: "It has been a convention of all literature and art that physical deformity, chronic illness, or any visible defect symbolizes an evil and malevolent nature and monstrous behaviour" or occasionally, disability is portrayed as something that a protagonist must "cope nobly with … but even then it is depicted as a "curse" to bear"(Dahl, 1993). Society's view of disability as a whole, independent of literature, is that disability is seen as "primarily a personal problem, afflicting individual people." Not only is disability seen as a "you problem," society often sees the cure as "strength of character and resolve." All of this, despite an increase in disability studies in the United States, and "decades" of disability rights activism. For example, a common activity at disability awareness and diversity events on college campuses are "disability simulation exercises." These exercises focus on the "failures and hardships" of disabled bodies and present the experience of being disabled as a "knowable fact" (Kafer, 2002). This perspective of disability as a whole determines how society views disability technology as well.

Interactions of the Actors in the Network

Disabled v Society

Society values good looking, "normal" people who contribute to the economy (i.e. hold down a job, participate in consumerism). In this way, value is quite literal. Because of the "limitations" imposed on them by their disability, disabled people are devalued and dismissed.

As is the technology that assists them. Society does not want to meet disabled people where they are, they want disabled people to come to them, to be more "normal." So it follows that society will value technology that makes disabled people look, act, behave, and more "normally." The more visible a disabled person's disability is, the less they are valued. The more severe a person's disability is, the less they are valued. Any technology disabled people use should be fancy, high tech, and cutting edge. As testified by cyborg author Jillian Weise, "They [society] want [disabled people] shiny and metallic and in their image" ("Common Cyborg," 2018).

For example, in the 1980's there was a group of disabled Canadian marathon runners who received extensive media attention.

> "While many marathoners crossed Canada for causes, it was only the young, attractive men with dramatic visual disabilities (Fox, Fonyo, and Hansen) who received orchestrated backing and media coverage. Promoters and handlers "packaged" the young man and directed the programs and publicity en route. A star was created." (Dahl, 1993, para. 7)

In this way, the media selectively covers disability and manipulates public response and creates so-called "heroes by hype" who fit their model of disability (Dahl, 1993). Obviously, not every disabled person fits this model, and those who don't often rebel directly against it. These models and societal definitions of disability constrain them.

In their work, *Transmobility: Rethinking the Possibilities in Cyborg (Cripborg) Bodies* Nelson, Shew, and Stevens provide a collection of "conversations" between the three authors, three disabled women. Before each outlines her own experience, they summarize the goal of their stories: "Our narratives reflect how people see us—and also how we respond, both in how we imagine ourselves and in how we free ourselves from their understanding." Disabled people

must not only struggle with the realities of their disability, but also with how society views them. They must fight to get society to view them the way they see themselves: capable through their transmobility, to see their condition as a "desirable orientation of body and mind." They recognize explicitly that these views directly oppose societal views and stigmas (Nelson et al., 2019). But they don't care.

The balance of power in this interaction is shifted heavily towards society. Society does not require disabled people to function, they are a minority. The power society exerts through media is potent and wide reaching. However, the media is also how disabled people can exert their own power. They can make noise, raise a racket, and draw attention to themselves. Show their own view of themselves to the world.

Disabled v Designers

While the balance of power between disabled people and society is tilted, the balance of power between disabled people and designers is a bit more balanced. Designers rely on disabled people to purchase their technologies, their jobs and financial stability depend on it. Thus, it is within their best interest to listen to the opinions and desires of the users of their technology. However, disabled people are still at a disadvantage. They rely on technology for their mobility, and therefore must take what is available to them. This results in disabled people using an amalgamation of available technology to be as mobile as possible: transmobility. Despite this, there is still some resentment towards designers from disabled community.

> "The cyborg is the engineer's dream. The engineer steers and manipulates the human to greater performance. As a common cyborg, I subvert that dream. I do not want to sell any of their shit for them. I am not impressed with their tech, … a leg that whirs and clicks, a

> socket that will not fit unless I stay in the weight range of 100-105 pounds… The last one they gave me was a lemon." ("Common Cyborg," 2018, para. 8)

The limitations of the provided technology enrage them. But they have no choice but to use it, and more importantly maintain it. This is a struggle, seeing as "things are not often designed to be maintained." Designers often, to some extent, "gatekeep" their technology, making it difficult to repair, maintain, or even modify (Earle, 2019).

The ability to repair, maintain, and modify their technology is only one way that disabled people can exert their own power over designers, or become designers themselves. As mentioned before, their opinions and desires are valuable to designers, if only they can get them to listen. And, should they like the technology from certain designers, their recommendations carry weight. By inserting themselves into the design process, cyborgs can exert some control over the technology created on their behalf. They are the experts, not the engineers or the medical professionals. The latter, at best, have a second hand understanding of the disability. The information that designers could acquire from their users is so extremely valuable, but many fail to do so.

Designers v Society

Society often lauds those who are involved with helping disabled people. Special education teachers, disability activists (who themselves are not disabled), and designers of disability technology. It puts these people on a pedestal for helping the helpless (at least, that is how society views them). But society also pushes its view of disabled technology on the designer, not just the disabled people who use it. Society values and likes technology that is shiny and fancy. It pushes designers to make such technology. Society loves a good revolution, especially in technology. Further, because society values people with certain disabilities more

than others, this higher precedence is pushed on to designers as well, prioritizing technology for those disabilities over other less flashy disabilities.

Good Design for Disabled People

It is important to treat disabled people with empathy and dignity, as it is for all people. But this is especially important when it comes to designing technology for them, or with them. Hosking, Cornish, Bradley, and Clarkson say it best: “Generating empathy within designers aids them in creating products to meet the needs of their users and could also assist in the design of medical devices to help patients maintain their dignity.” They also offer a methodology for empathetic engineering in medical devices. Empathetic engineering first requires utilization of empathy tools in order to connect with the user of the end technology, through direct and indirect contact. It also calls for protecting all elements of a user's dignity: privacy, control, choice, communication, and respect. (Hosking et al., 2015) This is the absolute bare minimum.

As mentioned above, disabled people struggle with maintaining and repairing their current technology and mobility aids. Designers must engage “with the cyborg bodies that currently exist, or those people who most reasonably may become cyborg soon – in every phase of production, from planning to distribution” in order to “produce the kind of cyborg future that they claim to want.” Otherwise they will continue to perpetuate the cycle of creating “better, faster, stronger” technology without addressing the shortcomings of previous technologies, as “upkeep rather than upgrading” is the norm (Earle, 2019).

Conclusion

In order to create good technology for disabled people, designers must forgo the mantra of “better, faster, stronger” and instead focus on making current technologies easier to maintain and repair. They must connect with users on a deeper level, and understand what users actually

get out of their technology. Designers must ignore societal expectations and desires for the shape, form, and function of disability technologies as they are often diametrically opposed to the needs and desires of the users. And in turn, society must let go of the "ideal" disabled person and accept all forms of disability, even the ones that aren't attractive. The balance of power in this network needs to shift away from society, and towards the disabled. This technology is for them. It should be designed with *solely* them in mind. The expectations of society must be wholly ignored. In time, society will shift, as it does by nature. Designers must design technology that is not necessarily shiny and new, but durable and user friendly. This technology should (if possible) be flexible and multipurpose — unitaskers are of little help. Designers must design for the disabled person as a whole, not just to their disability (more importantly what they *perceive* as their disability). Empathetic design is the goal, and while non-disabled designers will never fully understand the realities of day-to-day life for a disabled person, they should make every effort to understand why speed bumps occur and design technology that smooths them out. The resultant technologies will be better for the disabled, and allow them a more mobile and unimpeded life.

References

CDC. (2019, March 8). *Disability Impacts All of Us Infographic | CDC*. Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html

Common Cyborg. (2018, September 24). *Granta*. https://granta.com/common-cyborg/

Conceptual Models of Disability – PM&R KnowledgeNow. (n.d.). Retrieved February 5, 2022, from https://now.aapmr.org/conceptual-models-of-disability/

Dahl, M. (1993). The role of the media in promoting images of disability: Disability as metaphor, the evil crip. *Canadian Journal of Communication*, *18*(1), 75–80. http://dx.doi.org/10.22230/cjc.1993v18n1a718

Designer Definition & Meaning—Merriam-Webster. (n.d.). Retrieved April 15, 2022, from https://www.merriam-webster.com/dictionary/designer

Earle, J. (2019). Cyborg Maintenance: Design, Breakdown, and Inclusion. In A. Marcus & W. Wang (Eds.), *Design, User Experience, and Usability. Design Philosophy and Theory* (pp. 47–55). Springer International Publishing. https://doi.org/10.1007/978-3-030-23570-3_5

Hamraie, A., & Fritsch, K. (2019). Crip Technoscience Manifesto. *Catalyst: Feminism, Theory, Technoscience*, *5*(1), 1–33. https://doi.org/10.28968/cftt.v5i1.29607

Hosking, I., Cornish, K., Bradley, M., & Clarkson, P. J. (2015). Empathic engineering: Helping deliver dignity through design. *Journal of Medical Engineering & Technology*, *39*(7), 388–394. https://doi.org/10.3109/03091902.2015.1088090

Kafer, A. (2002). *Feminist, Queer, Crip*.

Mihailidis, A., Elinas, P., Boger, J., & Hoey, J. (2007). An intelligent powered wheelchair to enable mobility of cognitively impaired older adults: An anticollision system. *IEEE Transactions on Neural Systems and Rehabilitation Engineering: A Publication of the IEEE Engineering in Medicine and Biology Society*, *15*(1), 136–143.

https://doi.org/10.1109/TNSRE.2007.891385

Nelson, M. K., Shew, A., & Stevens, B. (2019). Transmobility: Possibilities in Cyborg (Cripborg) Bodies. *Catalyst: Feminism, Theory, Technoscience*, *5*(1), 1–20. https://doi.org/10.28968/cftt.v5i1.29617

The History of Mobility Aids. (2020, November 25). *ATLAS Surrey*. https://surreyatlas.uk/2020/11/25/the-history-of-mobility-aids/

Thomson, R. G. (2017). *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Columbia University Press.