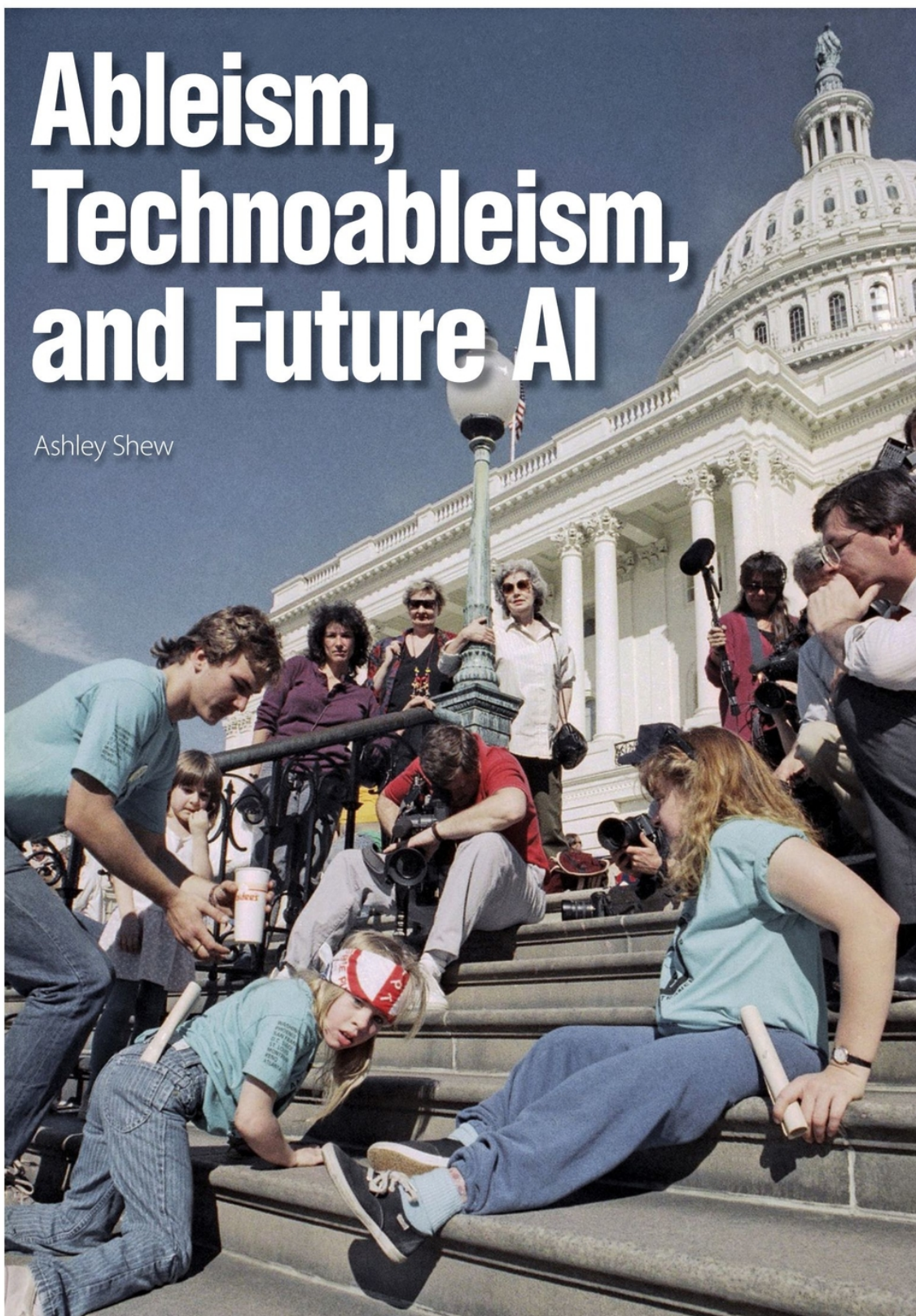


Ableism, Technoableism, and Future AI

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Capitol Crawl, Washington, DC, 1990.

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Ableism (discrimination in favor of non-disabled people and against disabled people¹) impacts technological imagination. Like sexism, racism, and other types of bigotry, ableism works in insidious ways: by shaping our expectations, it shapes how and what we design (given these expectations), and therefore the infrastructure all around us. And ableism shapes more than just the physical environment. It also shapes our digital and technological imaginations — notions of who will “benefit” from the development of Artificial Intelligence (AI) and the ways that those systems are designed and implemented are a product of how we envision the “proper” functioning of bodies and minds.

This article is divided into three parts. The first part explains what ableism is and how it warps our beliefs about what it is to be disabled. This section also explains reactions against a medicalized approach to disability, which informs some approaches to disability design, drawing from cases of design for disability that reflect implicit ableism. The second part of this article turns to ableism in technological development more broadly. It gives overviews of several case studies illustrating ableism in technological development and tech enthusiasts’ lack of interest in listening to disabled people’s ideas about and experiences with technology and disability. I will also unpack the concept of *technoableism*, a specific type of ableism around hyped and emerging technologies. This section examines the larger issues that influence how people imagine (or neglect) disabled bodies and minds when they set out to design new technologies. The third part turns to specifics, examining news coverage of AI and design, focusing on specific technological developments that extend ableist bias into emerging areas of design. This section discusses the relationship between disability and aging and examines home-based AIs aimed at an aging population, particularly the design of the interfaces between these AIs and the humans who are supposed to use them.

The ableist attitude that disability is always a negative and always an individual problem extends into our ideas about and designs for the ideal future. By considering the relationship of minds and bodies to communities and infrastructure, and by examining how ableism and technoableism currently affect our narratives about the world, we can anticipate and prepare for our technological futures as Artificial Intelligence and machine learning are sought as technologies for disability.

¹In this paper, I use identity first language (disabled person) instead of person first language (person with a disability). I identify as a disabled person. Other authors have written about this choice. See: (8), (26), (27).

Ableism

Many people see their disability not as a tragic event but as an important identity or experience in their lives. Common disability tropes — which depict disability as pitiful or shameful, as punishment for sin or wrongdoing, as obstacles to overcome, or as laziness or fakery — obscure the real experiences of disabled people and the sources of our frustrations. Ableism is a preference, explicit or not, for bodies and minds that are nondisabled and the resulting negative attitudes toward disability and disabled people. Ableism shapes our expectations and perceptions. These preferences (which may be obvious or subtle) against disability and disabled people are made manifest in the built environment and in the structural and social norms that shape daily life. Like other forms of bigotry and bias, such as racism, sexism, classism, and transphobia, ableism is a form of prejudice or bias.

Ableism underpins those practices and environments that *exclude* disabled people from community life (either intentionally or through poor planning and design), that *discount* first-hand accounts of the experiences of disabled people (often positioning nondisabled people as experts about disabled people), and that *marginalize*, or inhibit the contributions of, disabled people (for example, through teaching no disability history or teaching stories that perpetuate the notion of disabled exceptionalism).

Moving Against the Medical Model

While there are multiple models for how we might understand the interaction of bodies in the world, work in disability studies over the past thirty years has moved against the dominant model of disability, the medical model, which explains all disability as biological impairment. As historian Kim Nielsen (32) explains, “This framework considers disability to stem from bodily-based defects and tends to define disabled people almost exclusively by those diagnostic defects (and supposedly nondisabled people by their lack of such defects” (32, p. xiv). In this model, the appropriate response to disability is to try to rehabilitate, cure, fix, or otherwise alter the individual; when cures or fixes are not available, it pushes people who are disabled to perform, to try to pass for nondisabled.

In the medical model of disability, all impairments, whether bodily or mental, are *individual* problems to be addressed. The medical model’s focus on individuals detaches people from the larger context in which disability is constructed and deployed, and in which it must be understood. The medical model ignores the contexts, histories, identities, and social factors that have shaped the category of disability, instead pushing ideas of cure and proper performance back on individual disabled people. As phenomenologist disability studies scholar Tanya Titchkosky (45) explains it, “(i)ndividualized conceptions of

A person's relation to the world and to other people is central to how disability is constructed.

disability, such as the WHO's, require that impairment be treated as if it is the cause of disabled people's lack of participation in education, employment, leisure, and love" (45, p. 5). Rather than looking at the structures in which people are valued or not valued — the social, environmental, and designed world — the medical model points to individual failures to properly participate in education, employment, and social environments. It then attempts to normalize individuals for these existing environments using rehabilitation, treatment, and therapy.

In contrast, disability studies, which encompasses and connects disability history, literature, philosophy, and activism, places disability back into context. And the context is crucial — it creates the "norms" against which disability is measured. Titchkosky writes, "Some noticeable departure from the desired and expected is often taken as disability... One cannot be disabled alone" (45, p. 5). By taking disability out of context and isolating disability as a "problem" of individuals, we fail to address the real problems — the challenges literally built into the world — that disabled people face.

For example, certain traits are only recognized as disabilities in certain social and environmental structures. In a society where most people are illiterate, dyslexia will not be experienced as a problem, nor will people with dyslexia be socially isolated or face reduced opportunities. When a more isolated Martha's Vineyard was home to a large population of Deaf people and most residents knew sign language, Deaf people were not excluded or isolated. Similarly, in places that are appropriately designed, a person might find that a mobility impairment would cause no dramatic shift in their social life and would not limit where they could go. A person's relation to the world and to other people is central to how disability is constructed. For example, in U.S. society, the traits that are constructed as disabilities are (and have been) related to the economic value of one's labor on the market — to the ability to work. Nielsen's *A Disability History of the United States* (32) points to how notions about able-bodiedness and disability changed across American history as labor needs changed — ideas were constructed around who would be a valuable slave, who could work in a factory setting, and who could serve in the armed forces. Disability is always situated in context; it can never be truly understood as an isolated,

individualized problem, as the medical model suggests it ought to be.² This is not to say that disability never coincides with medical issues; chronic illness itself constitutes a disability, and many illnesses can lead to disabilities. My own disabilities, for example, were caused by treatment for cancer.

Disability Pride and the Narratives We Lack

Dominant cultural narratives (which shape the experience of living with disabilities) tell us that disability is an individual aberration, a pathology. We must resist these narratives. As philosopher Elizabeth Barnes reminds us, disability is a *mere-difference* (instead of a *bad-difference*):

The point is not... that there are no bad effects of disability. We are, all of us, limited by our bodies. Whatever way your body is, there will be bad effects of having a body that's like that. But the disabled body is a pathologized body. It's a body that departs from the "normal" in ways we assume are bad or suboptimal. Disability pride rejects this pathologization. As disabled people, we are forever being told that there is something about our bodies that is lacking, that is *less than*. Disability pride says it doesn't have to be that way. Disability pride says that we have *minority* bodies, but we don't have — we refuse to have — tragic bodies (7, p. 186).

Disability pride serves as an antidote to a culture that perceives disabled bodies as inferior. Disability pride movements and disability activism, which demand equal accommodation and opportunity, have united disabled people. There is no reason to put blind people in the same category as amputees and little people and people who experience bipolar depression — except that the world has been designed to exclude and other us. Our bodies or minds are abnormalized and stigmatized, and so we must band together (21). We have been lumped together by our assumed defects and deficiencies, but within this category is also power, pride, and resistance. Disability is a constructed category with great force.

Despite these movements toward identity, power, and pride, ableism still frames most people's understanding of disability and of disabled people. Indeed, most people don't even know about these movements. Disability history is not taught in most schools. People rarely learn about landmark acts of civil disobedience and demonstration from the disability community. For example, the longest

²Important to note, here, however, that the social model is not the only alternative to the medical model, nor is it the only possible alternative. Some disability studies scholars critique the social model and offer alternatives that recognize elements of the social model alongside embodied disability experiences like pain and other complexities. See (38) or (42), for instance.

sit-in in United States history was 1977's 504 Sit-Ins in San Francisco, aimed at pressuring the Department of Health, Education, and Welfare to enforce Section 504 of the Rehabilitation Act. (This sit-in was supported, in part, by the Black Panther Party and is a wonderful example of multifaceted civil rights activism. See [32, p. 169].) And during the Capitol Crawl in 1990, before the Americans with Disabilities Act was passed, demonstrators dropped their mobility gear, crawling up the Capitol Building steps to demonstrate the inaccessibility of buildings and institutions to disabled people.

ADAPT, an organization first created to demonstrate for accessible public transport in the 1970s, has become increasingly visible in 2017 and 2018, protesting (and successfully staving off) devastating healthcare reform that would have dismantled and destabilized programs important to disability healthcare, such as Medicaid. ADAPT protestors sat in congressional offices, were arrested in multiple states, filled congressional hearings, and even situated themselves outside Representative Paul Ryan's church to remind members of the Republican senator's community who his proposed budget would hurt.³ Images of blind and paralyzed protesters being dragged by police splashed the news. The disability civil rights movement is not finished, for issues of disability access have not been resolved.

Still, disabled people are omitted from history, or their disabilities are downplayed. In the United States, Helen Keller and Franklin Delano Roosevelt are often the only disabled historical figures that children learn about. They learn the "heartwarming" story of how young Helen Keller was helped by Annie Sullivan to communicate with the world, freeing Keller from her "prison" of isolation. Education about Keller emphasizes the importance of helpers, rather than Keller's competence (and that of other disabled people) when given opportunities, education, and agency. Students do not learn about the adult Keller's radical socialist beliefs (which grew out of her lived experience), her graduation from Radcliffe, and her voluminous correspondence all over the world — and they almost never learn that Annie Sullivan, the helper in these narratives, was herself blind, a fact that would trouble the ableist helper/victim dynamic.

Similarly, children learn about FDR, but the fact that he tried to pass as nondisabled is rarely addressed. As Daniel J. Wilson [47] puts it, "Roosevelt passed as a man recovered from polio who could walk and stand and was thus fit to hold high political office. In fact, FDR walked and stood with great difficulty and spend most of his time in a wheelchair or otherwise sitting" [47, p. 13]. There are only a few

pictures of him using a wheelchair, despite his nearly life-long wheelchair use. The message for his fellow polio survivors was to pass as best you could, to work as hard as you could in rehab to recover to the level that FDR apparently had. The narratives about FDR "overcoming" his polio reinforce the idea that all disabled people ought to pass as long as possible, especially at work and in school (for example, many disability communities urge disabled people to pass in job interviews if they can).

Aside from Helen Keller and FDR, the history taught in school rarely discusses the disabilities of other historical heroes, such as Harriet Tubman, whose disability is rarely mentioned in narratives about her life. Exceptions are made for some artists (who perhaps seem to stand outside of history); Frida Kahlo's works force you to confront disability (although the recent Frida Kahlo Barbie predictably erases her disabilities [22]).

Technoableism

Some disability activism confronts the ableist rhetoric that grounds many technologies being developed to cure or fix disability. These movements cannot be dismissed as simple anti-technology or nouveau-Luddism; they highlight the ableism in technological conversations, draw attention to the lack of representation of disabled people in socio-technical projects, and show developers' lack of awareness about the lived experience of disability. In this section, I describe several disability community reactions against particular technologies, approaches, and rhetorics around cochlear implants, approaches to autism charity, and exoskeleton devices; I then introduce the concept of *technoableism*, a term I have coined to describe a particular strain of ableism that I have witnessed in the context of imagination, technology, and bodies. Technoableism is a term I have coined to describe a rhetoric of disability that at once talks about empowering disabled people through technologies while at the same time reinforcing ableist tropes about what body-minds are good to have and who counts as worthy [31], [39]–[41].⁴ Technoableists usually think they have the good of disabled people in mind. They do not see how their work reinscribes ableist tropes and ideas on disabled bodies and minds. As we consider applications of Artificial Intelligence, it's important to recognize and work against ideas that reimpose and reinforce ableist claptrap under the guise of empowerment.

Cochlear Implant Controversy

One of the most notable recent cases of resistance to technology aimed at disability is the Deaf community's

³National ADAPT is great to follow on Twitter to find out about their actions (<https://twitter.com/NationalADAPT>) or can be kept up with through their website (<http://adapt.org/category/news/>).

⁴For work about bias across more types of difference in technological design (not simply disability-related), Damien P. Williams, blogging at *A Future Worth Thinking About*, has many good entries, including work on how neglect of folks in design can be a form of malice, and not merely neglect.

As we consider applications of Artificial Intelligence, it's important to recognize and work against ideas that reimpose and reinforce uninformed prejudice under the guise of empowerment.

reaction to the invention of cochlear ear implants, and particularly to the recommendation that they should be implanted in children. The Deaf community's reaction reveals both the ableism at the heart of the medical model of disability (ableism that the Deaf community calls *audism* — audism functions like ableism and is a preference for hearing folks over nonhearing, but not everyone who is Deaf considers themselves disabled).

The history of cochlear implantation and its impact on families has been covered in such documentaries as *Sound and Fury* (2000), *Hear and Now* (2007), and *Louder than Words* (2015). Historically, children who received cochlear implants were expected to participate in the hearing world, and the teaching of American Sign Language (or other signed language elsewhere) was often de-emphasized and often discouraged. Many, including doctors, saw cochlear implants as giving children more options by normalizing their communication. But those who take pride in Deaf identity and culture came to see cochlear implants as an affront to their culture: the implants were taking potential community members away before they had a chance to become Deaf.⁵

Many Deaf people do not consider themselves disabled — a fact that medical professionals did not anticipate. While “Professionals in implantation and many in the general public most likely agree that deafness is a disability and should be fixed,” Laura Mauldin (28) says, “These accepted norms around treating deaf children and the assumption they should learn to hear and speak are ... products of a larger culture” (28, p. 6). The Deaf community asserts Deaf identity as one of linguistic minority, not impairment (28, p. 7). This produces tension between hearing families who “want what’s best for their children” (who are often unacquainted with Deaf culture) and the Deaf community, which wants to continue to exist. Many audiology and hearing professionals did not recognize

this context and did not anticipate how disruptive cochlear implants would be.

I worry here about the ignorance of Deaf culture and Deaf life displayed by these professionals, who want to “help” but are not deeply committed to and immersed in the communities they purport to serve. The development of “sign language gloves” by people outside the signing community are a continued example of technological development that goes wrong in the absence of Deaf community interest, input, and consultation.⁶ Given the long history of audism and eugenics that deaf and Deaf people have faced (one where deaf people were subject to sterilization, sometimes kept from signing, and kept from each other), this cultural ignorance seems inexcusable. There are lessons here for designers who anticipate correcting or curing perceived impairments with AI: the main one is “know your audience” and also to include your audience as more than just mere audience or object.⁷

Autistic Self-Advocacy and Resistance

Other communities besides the Deaf community resist technologies that offer to “fix” their disabilities and erase their disabled identities. For example, there has been a surge of recent activism against Autism Speaks, a “charity” that has come under fire for ableist rhetoric and perspectives that exclude actual autistics and that focus on the insidious and demeaning language of “cure.”

Autism Speaks, which was founded in 2005 by Suzanne and Bob Wright, the grandparents of an autistic child (3), frames autism as a tragedy, one that desperately needs a cure. One early Autism Speaks ad epitomizes this scare rhetoric around “curing” autism. This infamous “I AM AUTISM” commercial features a gravelly voice narrating in the voice of autism:

I work faster than pediatric aids, cancer, and diabetes combined. And if you're happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain... I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without embarrassment, without pain. You have no cure for me. Your scientists don't have the resources, and I relish their desperation... I will plot to rob you of your children and your dreams. I will make sure that every day you wake up you will cry, wondering who will take care of

⁵Following the lead of the Deaf community, “Deaf” is capitalized here when it refers to the culture and lowercased when it refers to the inability to hear or lower levels of hearing.

⁶See Kouznetsova (23) for a good explanation of problems with the (multiply-developed) sign language gloves that make news every few years.

⁷Liz Jackson's work on Design WITH Disability (20) is important here. There are also other models of emancipatory research (as opposed to participatory research), such as (52).

my child after I die? And the truth is, I am still winning, and you are scared. And you should be ((2), as transcribed by (4)).

This commercial, which compares autism to AIDS, cancer, and diabetes, feeds on the worries of parents and loved ones by making autism seem like an awful fate rather than a neurological difference. This message may be especially frightening to viewers unacquainted with autistic adults or community. This “cure” rhetoric presents a problem for autistics who see their autism as an important part of who they are, and who do not wish to be non-autistic (51). Add to that the fact that Autism Speaks had no autistic members on their board for a very long time, adding autistic members only after great public pressure and scrutiny from autistic adults, and we see a situation like that of the Deaf community responding to cochlear implants: the actual people who are the object of a charity’s focus are alienated, othered, and misunderstood by that so-called charity.

The Autistic Self-Advocacy Network, a group run for and by autistic people, provides resources to help members explain the harmfulness of Autism Speaks (6). ASAN has collaborated with a long list of other disability rights groups, including the National Council on Independent Living, Not Dead Yet, Little People of America, and Down Syndrome Uprising to issue a joint statement against the practices and rhetoric of Autism Speaks (5). Many opponents of Autism Speaks point out funding allocation in the organization as evidence for their ableism. One self-advocate associated with ASAN writes:

... the majority (of their funding) goes towards causation and prevention. As a lot of that research is genetic in nature, prevention means research into selective abortion of fetuses with markers for autism. Not only does this not help autistics of any age, it encourages the idea that it’s better to not exist than to RISK being disabled (and in particular, autistic).... (37).

This is eugenics aimed at eliminating people who would otherwise be part of the autistic community, and Autism Speaks’ focus on genetic research and autism prevention weigh heavily on advocates.

Autism Speaks is a very large autism charity; both its focus and its familiar branding — the blue lights, the iconography of the missing puzzle piece — set norms for other autism charities. Therefore, activists’ worries about Autism Speaks also carry over to other organizations that investigate autism and its causes. Autistic people are now speaking up against technologies of cure before they are made, as autistic self-advocates assert the value of their lives — and of the lives of disabled

people more broadly.⁸ The history (and present) of eugenics haunts the rhetoric of those who seek to cure or fix disabilities of all kinds.

Reactions to Exoskeletons

The much-hyped exoskeletons — technological mobility “suits” designed to enable users with particular types of mobility impairments to independently do certain types of physical tasks — have also been an object of critique for those in disability communities. When a person using an exoskeleton kicked off the first ball for the World Cup in 2014, many nondisabled commentators were thrilled. However, many disabled people were less excited. *New Mobility*, a magazine for active wheelchair users, did a roundup of quotes from the blogs of wheelchair users. User Red Nicholson was quoted as saying, “So hey, able-bodied media: quit making me feel like wheelchairs are a shitty, sub-par option.” And Shane Clifton wrote, “If science wants to help me out, it should concentrate its research on the bladder and bowel, and do something about nerve pain and spasm” (9).

Disability Studies scholar Bill Peace has written about the problem of exoskeletons and the meaning and importance of wheelchairs:

Typical news stories consider the exoskeleton a “miracle” that enables paralyzed people to walk again. References to Iron Man abound as do comparisons to being “wheelchair bound” versus being a “super hero.” The message is not subtle: walking is the best means of locomotion. Using a wheelchair is inherently bad. A wheelchair is an antiquated piece of technology and the exoskeleton is here to rescue paralyzed people who are “bound” to their wheelchair (33).

These disabled people’s reactions to the exoskeleton technology often shock students in a class I teach on Technology and Disability. Given the media sensation that exoskeletons have created (from the World Cup stunt to multiple TED talks and news articles about their potential for helping paralyzed people), nondisabled people often have not reflected on how these devices are situated and understood and about the ableist worldview that drove the technology’s development.

The full story of exoskeletons has yet to be written, but the existing narratives around paralysis (framed as an awful fate) and walking (assumed to be the best way of

⁸An interesting facet of how autistic self-advocacy has developed is that unlike in the Deaf community, autistic advocates and activists aren’t pushing against the label of disabled. They promote a social model in which people accept that they are both disabled and a part of normal distribution of human variation. The neurodiversity paradigm and movement has helped contextualize the diversity of neurologies as a simple observation about human variation, rather than a pathological condition.

moving through the world) almost seem designed to end with exoskeletons as a solution to the “problem” of mobility impairment — a technoableist’s dream solution. Yet exoskeletons aren’t the cure-all imagined by the news stories in which they are featured [13], [26]. And actual wheelchair users — the people for whom the devices were ostensibly developed — point out that nondisabled people are often mistaken about what is bad about being a wheelchair user. Wheelchairs themselves are not the problem; as Peace put it, “From my perspective, I think a wheelchair is a phenomenal invention” [33].

The real problem with wheelchairs is accessibility, both environmental and economic. Many places remain inaccessible for wheelchair users (despite legal accessibility requirements, which are poorly or simply not enforced), and wheelchairs are economically inaccessible to many (good wheelchairs are costly and difficult to repair — and just imagine how much worse exoskeletons will be to maintain and repair⁹). The fanfare over exoskeletons puts the focus on mobility devices rather than other problems faced by paralyzed people. Rather than spending money developing alternatives to wheelchair technology, which works very well, other effects of paralysis should be examined by scientists and technologists, as the blogger Shane Clifton (quoted above) pointed out [9]; why can’t a tech designer create a workable device to help with bowel and bladder control or nerve pain? These are a much bigger problem for many wheelchair users than the chair itself.

Disability studies scholar Kim Sauder identifies the key reasons why the fanfare around standing wheelchairs and exoskeletons is problematic for those in the disability community. First, Sauder says, “able-bodied people ignore the cost of these devices,” which would usually “be shouldered by the disabled user.” Second, Sauder points out, many of the exoskeletons are very limited; for example, she says, the Tek exoskeleton “is only useful indoors so an alternate mobility device is required outdoors.” And exoskeletons will do nothing to increase accessibility for non-wheelchair users who have other mobility impairments. These people “may also need additional space to maneuver or ramps,” and exoskeletons do nothing to make the broader environment accessible to everyone. Third, the fact that exoskeletons ignore the possibility of “making the actual social environment more mobility friendly” instead puts the problem back on the individual disabled person, reinforcing the ableist medical model of disability: “It positions the disabled body as social space where others can enact changes to mobility,” which “ignores both the autonomy of disabled people and the fact that many of us don’t want to be ‘fixed’ either by cure or imposed treatment.”

⁹Joshua Earle has some forthcoming work on “Cyborg Maintenance” that talks about this exact problem with current technologies.

Finally, Sauder notes that the entire concept of exoskeletons “associate(s) an accessible environment to disability (therefor [sic] rendering it ‘other’ and undesirable)” [36].

Exoskeletons only look like a solution when wheelchair use and paralysis are couched as individual problems, rather than problems of our infrastructure — of who we include in our visions of the environments of the future. This exoskeleton narrative ignores the fact that many wheelchair users are not paralyzed. Even if this technology were affordable (it probably won’t be), it still would do nothing for the real problem as nondisabled people see it: the fact that people use wheelchairs. The huge number of non-paralyzed wheelchair users would still be around, asking for more curb cuts and door openers, reminding nondisabled people that people with disabilities exist. And the hype about exoskeletons as solving the “problem” of paralysis is completely misplaced — the way that the technology has been marketed, promoted, and hyped is more a reflection of ableism than of the devices’ real value, which is for non-paralyzed people. Exoskeletons could be remarkably useful as safety devices (they are currently being tested for workers in home improvement stores, who have to lift heavy things), and people report that the devices can be successfully used in physical therapy rehabilitation for people who have had strokes, supporting them as they practice different movements to regain strength and balance. But these uses for exoskeletons — as support devices for older people doing post-stroke rehab or as expensive lifting belts for workers at your local Home Depot — are much less techno-redemptive, for these workaday uses for exoskeletons don’t fit into our (ableist) visions of a techno-utopian future.

Technoableist Dreams of Cure and Passing

Disability and technology must be situated within the social, historical, and cultural stories we internalize, which usually show that disabled technology users are empowered, liberated, or normalized by technology. This is the rhetoric that is embodied in the controversies over cochlear implants, autism charity work, and exoskeletons — case studies that make clear how supposedly well-meaning people can make mistakes in imagining the needs and desires of the communities they purport to serve.

Even members of those communities, though, can get it wrong. Ableism is a system of value that all of us participate in, including individual disabled people. And internalized ableism might be even more common among disabled people who (like me) are not born with disabilities, but become disabled during the course of their lives. Disability is a category that can come to apply to anyone, and people who are already disabled might enter new categories of disability at any time.¹⁰ Systemic

¹⁰Here I think of my amputee pal Mallory Kay Nelson who, upon recounting to me how she became an amputee, added “of course I’ve always been dyslexic, so I have been a part of the disability community for much longer” [30].

forces and cultural narratives about what constitutes a good life often limit the ways that disability can be imagined, none particularly desirable. Dreams of passing, of “normalcy,” and ideas about inspiration and overcoming, frame many of the disability community’s internal conversations about disability technologies.

These internal divisions are apparent in the conversations being had about genetic testing for disabilities and the new technologies that make it possible to edit genes — to “fix” or “cure” genes with “problems” before a baby is ever born. David Perry and Alice Wong have written (34), (50) and spoken about the moral challenges posed by these new CRISPR gene editing technologies. David Perry made his position clear with the title of his article, “We’re Failing Our Test Run for the Age of CRISPR,” which was widely shared within disability groups:

I’ve contended that the past decades of testing, genetic consultation, and decision-making about abortion related to prenatal diagnoses of Down syndrome have served as a kind of test run for the future of human procreation. Can we make informed choices? Can we understand that probability doesn’t equate to outcome when we’re talking genetic makeup? Can we use science to build a more just, happier humanity? (34).

Perry concludes that the answer is no. Not only are we not making communities that are happier or more just, we can’t even build communities that can see that disabled lives can be worth living. The value of disabled lives, and the sheer joy of living (which is experienced in whatever body you have), are expressed by Alice Wong, co-founder of the Disability Visibility Project, in a talk at Stanford’s MedX Conference:

Because of my apparent physical disabilities, many people, both strangers and acquaintances, presume that my life is one that’s difficult and full of suffering. I am totally dependent on personal assistance for my daily activities and cannot breathe without ventilator support. For some people, this is an undignified, unimaginable, and pitiful way of living. Some of these people would rather be dead than be in my position based on perceived loss of control, weakness, and fragility. And that’s ableism. Yes, I experience pain and suffering but that doesn’t mean my life isn’t rich and full. Yes, I need a lot of help, but that doesn’t mean I can’t make decisions for myself on how I want to live (50).

Although the history of disabled people is one full of eugenicism, institutionalization, and active discrimination, and although many disabled people still face

limitations on their employment options (through sheltered workshops and employment discrimination) and many cultural biases, people with disabilities need not believe in the cultural narrative that disabled people’s lives will be tragic, difficult, or otherwise poor. Many of us enjoy our lives, and the technologies that support us. Many wheelchair users write of the joy of their machines; I love both my prosthetic leg and my shiny, blue wheeled walker. Alice Wong writes: “Technology has made a huge difference in my life. Power wheelchairs, Bi-Pap machines, the Internet have made my life what it is today” (50). Disabled people aren’t nouveau-Luddites, but technologists often stereotype us this way. Instead of imagining the desires of disabled people (through the lens of ableism that we have all internalized to some degree), why don’t technologists simply *ask disabled people* what kinds of technological applications we want and need?

Listening to disabled people produces better technologies and design of resources and infrastructure for everyone. When people design for disabled people — when they design technologies to work for people whose bodies and minds run a wide gamut — the designs are better, and more people (including nondisabled people) like and adopt them. As one disabled designer, J.H. Adamé, puts it:

It’s this ableist thinking (if the problem doesn’t apply to me, it must not exist) that has limited development in these fields for so long. If we allow the voices of our most challenged users to be heard, solving a huge problem for some can mean solving an inconvenience for everyone else. Inevitably, inclusive design benefits all of us. When we factor in the people at the extreme ends of use, we end up making something that is easier for the folks in the middle as well (1).

Building things for disabled people often means building better things for all people — a principle that also applies to the built environment. An environment that is accessible to the “extreme ends of use” is a world that is more easily navigable and more comfortable for everyone — including nondisabled people, such as parents with children in strollers, athletes with broken arms, the temporarily injured, and so many more.¹¹

Artificial Intelligence

The latest set of technological solutions to the perceived problems of disabled people is Artificial Intelligence and machine learning. But like other technologies discussed

¹¹There is a large body of literature on the benefits of Universal Design (an approach that considers design for a wider range of bodies and minds) — though, one should note, disabled people should not be valued only because their inclusion produces better products for everyone.

in this essay, Artificial Intelligence research and AIs currently under development contain several inscriptions of technoblesism that I want to warn against. I also want to gesture to an emerging frame for considering appropriate disability technology, called Crip Technoscience [16].

The current mood is one of optimism about machine learning and Artificial Intelligence for disability applications. Headlines scream about it: “How AI Could Transform the Lives of Disabled People” (10), “How Artificial Intelligence Can Help With Disabilities” (19), and “Artificial Intelligence Poised to Improve Lives of People with Disabilities” (46). Sometimes these headlines acknowledge AI’s potential for helping people as they age (correctly assuming that older folks are more likely to have disabilities), hyping the potential for robot caregivers and AI emotional support “animals” — AI that can take the place of human carers or friends, often at a lower financial cost: “Artificial Intelligence Could Improve How We Age” (29), “Can China Win the Artificial Intelligence Race by Serving the Elderly?” (18), and “Robot Caregivers are Saving the Elderly from Lives of Loneliness” (43).

These breathless headlines make clear the assumptions that ground the articles that follow them — assumptions about what it is to be disabled and what it is to age. (These articles tend to lump disability and aging together, and I therefore examine the two together, but there are important differences between these demographic groups in terms of stigma, access, convenience, societal narrative, and consideration.) Like earlier technological interventions on disabled lives, these technologies rely on assumptions about the disabled and aging *individual* rather than the environment. For example, ideas about the importance of independence factor heavily into coverage of AI for disabled and older folks, and are particularly clear in discussions around autonomous vehicles, companion robots (like *Paro*), home-based applications (like *Alexa*), and caretaking robots. All of these technologies emphasize aging and disability as problems for individual consumers, rather than problems for society.¹² Why should the lack of accessible transport for people who cannot drive be a problem for the non-driver rather than for society? Why should the loneliness and isolation experienced by people who cannot easily leave their homes be solved by in-home robots rather than by better planning and infrastructure within our communities?

¹²This is not unique to AI, of course. There are many existing technologies and gadgets that were originally designed to increase the independence of disabled and/or aging users and that contribute to ease of independent living for all people: kitchen gadgets that arthritic hands can hold (the OXO line is designed on this premise), hot water heaters that don’t require the lifting of a heavy tea kettle [11], grabbers and reachers, pre-cut and pre-peeled fruits and vegetables, medical alerts, handrails and ramps, mobility devices, and accessible bathrooms. All of these technologies were designed to increase disabled people’s independence, and they all also enable aging in place with more independence. Liz Jackson’s *New York Times* article “We Are The Original Lifehackers” is a must-read on this topic: <https://www.nytimes.com/2018/05/30/opinion/disability-design-lifehacks.html> [20].

AI designers are clearly focused on changing the individual to fit the environment rather than the other way around. For example, many of the “conveniences” offered by AI applications are mostly conveniences for the benefit of the user’s family, rather than the users themselves. These technologies are framed as unburdening families from worry by enabling them to remotely monitor or check in on their loved one’s condition; as reducing the financial costs of hiring human caretakers; and as combating the user’s isolation and loneliness, thus requiring fewer visits from family members. When AI technology is framed as helping the family, it positions disabled and old people as recipients of care rather than as agents in their own lives, and it decenters them and their experiences, instead moving the nondisabled family members into the center of the story (which also fails to recognize that disabled people can have disabled family members and can be caregivers themselves).

This same centering of ability is produced by the narratives’ focus on *independence* as the main goal of disability design. Indeed, the nearly obsessive focus on independence is another “tell” for ableism. As Elliott Kukla writes:

We are born needing care and die needing care, and I am no exception. At brief moments in the middle of life, we hold the illusion of independence, but we are always driving on roads we did not build, eating foods we did not pick or raise. Allowing the illusion of my own independence to drop away unmasked a fundamental truth of being human [24].

This sentiment echoes throughout current disability studies: we are all interdependent, and independence has always already been an illusion.¹³ But disabled and old people have often needed to advocate for independence, because they have historically been the subject of laws, *de facto* rules, and public norms that deny them full citizenship, access, and opportunity to participate in public life. For example, early disability activism of the 1970s and 1980s produced a movement called the independent living movement. The name — independent living — indicates a reaction to the historical framing of disabled people as completely *dependent*, as objects to be moved around by nondisabled people. Despite the name, this movement was not about independence in the sense of isolation, total responsibility for one’s own needs, and total avoidance of inconvenience to nondisabled people — the values that underpin current narratives about AI. Instead, the movement was about the right to a public life, a life outside of institutions — an *interdependent* life. It demanded community living (the slogan “Our Homes, Not Nursing Homes!”),

¹³There is a good discussion of this in Sunaura Taylor’s *Beasts of Burden* (44) and Leah Lakshmi Piepzna-Samarasinha’s *Care Work* (35).

access to education and to public spaces (schools, grocery stores, shops, etc.), vocational services (to enable people to work), and assistive technologies (to help people move and remain outside of institutionalized and segregated care). The independent living movement demanded only that disabled people have the same autonomy, rights, and freedoms that nondisabled people enjoy.

Interdependence (neither isolationist independence nor dependence) is a central value in the Crip Technoscience Manifesto. It is the second item on the list: “Crip technoscience is committed to interdependence as a political technology” (17, p. 12), and the Manifesto itself, which is “premised on interdependence,” was written to describe the “core values” of crip technoscience. According to Hamraie and Fritsch (16, 17), crip technoscience blends critical disability studies with approaches from the field of Science and Technology Studies (STS). It anticipates a world in which disabled people are seen as experts about their experiences and the materiality and context of their bodies. Crip technoscience anticipates accessible futures that work not toward cure or normalization but toward freedom.

AI as a disability technology also presents particular problems of data privacy, especially given the long and ongoing history of the policing of disabled bodies. For example, the recently deployed Electronic Visit Verification (EVV) technologies enable personal care attendants (PCAs) to clock in and out of their home health visits. Under EVV, these personal care attendants, who provide physical support for disabled people to accomplish daily tasks (toileting, prepping food, getting in a wheelchair), are issued mobile phones to track their time on the job. But disability activists express worry about the scope of the monitoring enabled by this technology. As disability activist and filmmaker Dominick Evans tweeted:

It is a pure violation of the civil liberties and personal freedom of disabled people across the United States.

Our PCAs are now being equipped with something equivalent to an ankle bracelet by the US government!

They are giving (sic) phones that have cameras in the front and the back so they can track exactly what all of us who need homecare are doing. They could record any conversation.

These devices have to stay in our homes, at all times. We'll never know when they are recording, and we don't know who has access to them beyond the monitoring company, and government agencies.

It's a huge threat to the personal safety of disabled people who require home care (12).

The use of EVV technology is a huge invasion of privacy — an invasion that would not be permitted for many segments of society.¹⁴ Can you imagine if any nondisabled, noncriminal citizen was required by the government to allow a device with the potential to monitor them in their homes at all times? This is precisely what some of the proposed AI technologies will do. And disabled people — especially disabled people who are multiply minoritized, whose identities are more carefully scrutinized by others — are rightfully concerned. Our society does not value the privacy of older people and disabled people,¹⁵ and many of the AIs in development sacrifice this privacy in favor of the peace of mind of presumably nondisabled caretakers — an assumption that disabled and old people are not agents in their own right.

Experiences of Real Disabled People

The crux of the problem is that AI designs, like other technologies meant to address disability issues, are often spearheaded by people not deeply embedded in the disability community — people who simply imagine what it might be like to be disabled or elderly rather than base their design on the experiences and needs of real disabled people. These designers, who are usually ignorant of the larger history of disability, often reinscribe ableism in their designs, further stigmatizing and marginalizing disabled people through monitoring or tracking or decision-making by proxy. The typical framing of new technologies as promoting independence is based on a lie: the lie that any of us is truly independent. These technologies are touted as empowering, but designing technologies without consulting their user base is the ultimate in disempowerment.

One of the commitments of the Crip Technoscience Manifesto is to center “the work of disabled makers and knowers” (17, p. 7). Tech designers’ reliance on their imagination of what it is to be disabled¹⁶ keeps the focus on individual functioning and limitation, rather than addressing the larger context — the poor infrastructure and social stigmas that work against the full participation of disabled people in society. This is not an either/or situation: we can *both* work to support individuals’ particular interests and needs *and* work to create a more accessible world for all

¹⁴D.E. Wittkower has done some wonderful work on how to reframe privacy agreements and licenses for software in a way that fosters trust, especially in reference to how to deploy technologies like RIBA (meant to help lift and toilet people), Alexa and Google Home (developed not with disability in mind, but being adopted fruitfully by some disabled user groups), PARO (the interactive seal meant to help dementia patients), and Nest (a smart home technology). See (48), (49).

¹⁵Given the rise of the number of viral videos and pictures of good-nice-nondisabled people helping unnamed disabled people at some task — with praise for that saint of a nondisabled person — that come through my social media each week, the causal belief and message that disabled people don't deserve privacy is quite clear.

¹⁶A technologized version of this kind of imagining (instead of asking) is designers’ participation in disability simulation; see (13) for discussion of this in relation to virtual reality.

Designing technologies without consulting their user base is the ultimate in dis-empowerment.

people. But we cannot do either if we continue to design technologies that reinscribe the "cure" or normalization of individual disabled bodies and minds instead of making worlds more conducive to our existence.

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