

Combating Ableism: Disability Advocacy in the United States

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by

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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

In the United States, roughly one in four people have some type of disability; about 12 percent have a disability that impairs their mobility (CDC 2023). A physical disability can limit an individual's access to healthcare, employment, and education, compromising personal independence and social participation (Morelli 2023). By diminishing these constraints, we improve individual lives and foster a more inclusive society that values every person. Since the mid 20th century, the disability rights movement in the US has achieved major reforms, including the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 (Meldon, 2023). Yet inequities persist, however, especially in access to employment, technology and healthcare, and as obstacles to personal and financial independence. In the US since 2010, persons with physical disabilities, the advocacies that represent them, federal agencies and other social groups have pursued initiatives and public policy to better serve the needs of the disabled. They have pursued legislation to ensure accommodations, demanded funding for disability research, and centered the voices of disabled people. Against arguments that many accommodations are unnecessary or too expensive to provide, disability advocates have invoked legal doctrines such as equal justice under law, philosophical principles such as human rights, and ethical values such as social equity.

Review of Research

Researchers have explored how access to transportation can impact a person's access to other societal resources. For example, Wellman (2015) found that disadvantaged groups who do not have access to transportation lost access to employment, education, and healthcare services. Wellman studies transportation equity and how access to transportation reflects an

administration's social values. While Wellman focuses on the effect this has on the poor, drawing a similar conclusion in the topic of disability advocacy, if a city does not provide adequate transportation accommodations for people with disabilities they do not value them in their society. Others see social justice as a moral issue. Baechamp (1976) argues "our most intractable public problems have two significant characteristics". The characteristics are that these issues "occur to a relative minority of our population (even though that minority may be millions of people)" and are "providing substantial benefits or advantages to a majority or to a powerful minority of citizens". In terms of disability advocacy, many powerful organizations are unwilling to solve issues of equity for disabled people because it means giving up their resources such as time, space, and most of all, money. There is also an awareness and educational component to this problem. According to Morelli (2023), there are far fewer healthcare providers that feel equipped to treat patients with disabilities due to a lack of comprehensive medical education. Morelli stated that in a poll of US physicians, "only 40.7% felt very confident in their ability to provide the same quality of care, overall, to patients with disabilities". This disparity in quality of care to disabled and non-disabled patients is just one area where people with disabilities' needs are not being met at the same level as the rest of society and is the reason disability advocacy is required. While there is opposition to disability advocacy, mainly for financial reasons, some researchers believe that in order for a society to fully flourish there needs to be equity for all. While many cities do not focus on disability equity, there are "some exemplary local government officials" who have "worked in partnership with businesses, non-profit organizations, community organizations, and residents to collaboratively develop programs to create more vibrant, resilient communities" (Svara, et al., 2015).

Societal Changes and Accommodations

In order to bring about change, many advocacy and lobbyist groups have been formed with the goal of protecting the rights of disabled people and championing social reforms across the country. One Chicago based advocacy group, that functions primarily at the state level, is Access Living. In order to accurately fight for the needs of people with disabilities, Access Living's "diverse staff and board are made up of mostly people who have disabilities" because they believe that "people with disabilities are their own best advocates" (Access Living, n.d.). Like many disability advocacy groups, they follow the mantra "nothing about us without us". Through lobbying the Illinois state government and providing services for local people with disabilities in Chicago, they promote their message that "people with disabilities have the right to live the lives they choose for themselves, in an accessible, integrated world" (Access Living, n.d.). Some of the services they provide to Chicago residents are housing services, youth programs, consultations for businesses and nonprofits, and legal services (Access Living, n.d.).

Another group that fights for the rights of disabled people is Disabled in Action (DIA) based in New York, New York. Their mission is to advocate for and protect the rights of people with disabilities living in or visiting New York City. One way this is accomplished is through lobbying. Members of DIA say, "we speak at presentations, we write letters, send emails and texts, make phone calls, join webinars, video conferences and conference calls" to influence local businesses and government agencies (Disabled in Action, n.d.). Another way they do this is through in person protests. The DIA hold a "monthly rally at the MTA for elevator maintenance" to ensure that everyone has the same opportunity to use the public transit in and around the city (Disabled in Action, n.d.). A third way is through filing lawsuits. They use the ADA as grounds to fight for accessibility improvements and "Currently, DIA is involved in four subway access

lawsuits as well as other lawsuits concerning pedestrian ramps, police station accessibility, and yellow taxi accessibility” (Disabled in Action, n.d.).

Since 2010 in the US, many states in the US as well as federal agencies have responded to this societal pressure from advocates for people with mobility related disabilities in the forms of passing legislation and changing requirements. In the past decades, there has been progress made to expand the Americans with Disabilities Act of 1990 and increase accessibility to those with disabilities. In 2013, the Department of Transportation issued new rules that required all airlines to give wheelchairs priority in storage closets over other luggage. It also allowed them to store additional wheelchairs using seat strapping which is, “placing a wheelchair across a row of seats using a strap kit that complies with applicable Federal Aviation Administration (FAA)” (US Department of Transportation, 2013). In 2012, the US Department of Justice published new rules and guidelines under the Americans with Disabilities Act extending accessibility regulations to swimming pools. The new regulations gave all pools located at “public accommodations” until January 31, 2013 to install a fixed lift to help disabled individuals with entry and exit of the water (US Department of Justice 2012). Laws and regulations such as these have improved disabled peoples’ ability to use public spaces and move independently around the world.

In addition to mandates that improve accessibility, there have been state laws passed that improve disability awareness through education. In 2011, the governor of Delaware signed a bill designating October as “Disability History and Awareness Month” which encourages schools in Delaware to, “informally offer instruction and events highlighting disability history and awareness” (Delaware Governor's Advisory Council for Exceptional Citizens, n.d.). The passing of bills like this improves people’s understanding of disabilities and increases the level of

compassion towards people with disabilities which in turn will lead to more accommodations and future laws to be passed.

Funding of Research

Another way that people with disabilities and their allies advocate for change is through the funding of research that aims to improve their conditions. One example of this is the Christopher and Dana Reeve Foundation. After becoming paralyzed from the neck down, actor Christopher Reeve started a foundation that has “invested more than \$140 million in research” to “achieve our ultimate pursuit – cures for spinal cord injury” (Reeve 2023). The organization's mantra is “today’s care, tomorrow’s cure” (Christopher & Dana Reeve Foundation, n.d.). While “tomorrow’s cure” is based on research studies, to further “today’s care” they provide people who have suffered paralysis with resources on rehabilitation, health insurance, caregiving, and support groups (Christopher & Dana Reeve Foundation, n.d.). While he was somewhat controversial in the disability world, Christopher Reeve’s foundation has been involved with many studies that aim to repair the central nervous system and in 2019 partnered with medical technology company ONWARD (Christopher & Dana Reeve Foundation, n.d.).

The Miami Project to Cure Paralysis is a program through the University of Miami Miller School of Medicine that is developing new treatments for spinal cord injuries and disorders and are “dedicated to improving the quality of life and, ultimately, finding a cure for paralysis” (The Miami Project to Cure Paralysis, n.d.). Their research currently includes studies focused on cell therapy, exercise science, and fertility in men with spinal injuries. The Miami Project was founded by neurosurgeon Barth A. Green and former NFL linebacker Nick Buoniconti. To get the program off the ground, “the Buoniconti family established The Buoniconti Fund to Cure

Paralysis in 1992. The Buoniconti Fund is a non-profit organization whose primary focus is to raise funds and awareness to help The Miami Project to Cure Paralysis achieve its national and international goals” (The Miami Project to Cure Paralysis, n.d.). Anyone is able to donate directly to this fund and the program hosts fundraising events like the “Annual Celebrity Golf Invitational” which “brings together some of the world’s top business leaders and celebrities as they join forces to find a cure for paralysis” (The Miami Project to Cure Paralysis, n.d.). The program also receives grants from organizations with interest in spinal cord research including “funding for Dr. Ganzer from a NIH R01 grant for \$2.4 million will allow his team to explore upper extremity recovery following VNS paired with rehabilitation (VNS+Rehab) therapy” (The Miami Project to Cure Paralysis, n.d.).

Both the Christopher and Dana Reeve Foundation and the Miami Project to Cure Paralysis were started by people who had personal connections to the disability world. Christopher Reeve himself became paralyzed in a car accident and Nick Buoniconti’s son Marc “sustained a spinal cord injury during a college football game” (The Miami Project to Cure Paralysis, n.d.). In addition to privately funded research, the National Institute of Health (NIH) has also been influenced by social pressure and allocated over \$2 million in funds to the Interagency National Robotics Initiative (NRI) to develop assistive robotics for people with disabilities (NIH, 2014). This includes research by University of Michigan professor Brent Gillespie who is working on wearable robots that assist in the rehabilitation of limb function (Gillespie, 2018).

Combatting Technology Related Ableism

While there are many supporters of research with the end goal of eliminating mobility disabilities, many within the community are opposed to the idea that their disability is something that needs to be fixed. Christopher Reeve, whose foundation has raised millions to fund research to cure paralysis, is often at the center of these criticisms. Blog posts from William Peace, a paralyzed disability advocate and a vocal opponent of the Christopher Reeve Foundation, said “Christopher Reeve never understood disability. He carefully separated himself from other people with a disability” (Peace, 2016). In this entry, Peace’s main qualm is with the support the foundation gave to the movie *Me Before You*, which ends with a quadriplegic committing physician assisted suicide. Peace is upset because, in his opinion, the foundation is affirming “the assumption that death is preferable to disability” (Peace, 2016). Peace further states that “the Reeve Foundation taps into the myth that people who are paralyzed overwhelming desire is to walk again. Sorry, but no.” and that most people he knows just want to “adapt to disability and move on with life” (Peace, 2016).

What many people are opposed to is the idea that disability needs to be cured through technology. In her book *Against Technoableism: Rethinking Who Needs Improvement*, author Ashley Shew coined the term “technoableism” which is “a belief in the power of technology that considers the *elimination of disability* a good thing, something we should strive for.” (Shew, 2023). One of her main objections to the current technology industry is that “disabled people are almost never included in discussions about what technology means and how it integrates into daily life, what it means to be human in our modern world.” (Shew, 2023). She gives an example of scientists developing robotic hands without ever talking with amputees. Shew furthers that “When people assume that one device will ‘fix’ us, they don’t pay attention to the host of other concerns around disability technology” (Shew, 2023). She goes on to argue that people want

disabilities to be “fixed” so that they can turn a blind eye to many other issues like poor facility design, ongoing maintenance of accommodations, high personal health costs, and lack of social support (Shew, 2023).

In an opinion piece in the *The Stanford Daily*, Stanford University student Cricket Bidleman describes the technology related ableism she faces as a blind student who uses a cane. Bidleman talks about a new “smart cane” technology that was featured in the Stanford Report and how many of her peers assumed she would be all for the design. This was far from the case as she had issues with its weight, price, and the motivation for its creation (Bidleman, 2021). These issues made it clear to Bidleman that the people responsible for the “smart cane” did not consult with any blind people before creating it. To start, the “smart cane” weighs over three pounds while Bidleman’s current cane weighs less than one, and makes her worry that “the heavier weight of the ‘smart cane’ puts undue stress on users’ wrists and arms” (Bidleman, 2021). Additionally, it costs over \$400, a price Bidleman says most blind people could not afford, while there are many resources that provide traditional canes to blind people for free. Bidleman says it is clear to her that creators of this device did not fully have accessibility in mind as the promotional videos they made do not include audio descriptions of their contents and believes “It is extremely hypocritical to brag about accessibility efforts for blind people in videos that don’t contain audio description” (Bidleman, 2021). Like other people who criticize technology related ableism, Bidleman believes that there are many other issues that need to be addressed first like fair wages, sexual assault, and disabled people being denied services due to their disability and that we need to “get off those high horses of high tech and instead spend our energy on fixing these issues” (Bidleman, 2021).

Opposition to Inclusivity

While there are no organized groups that actively oppose disability rights, there are groups and individuals who hinder progress due to being misinformed, having opposing business interests, or a general dislike of inclusive policies. Many local and state governments do not prioritize people with disabilities in their budgets which leads to a lack of inclusive infrastructure and accommodations. In New York City, the Department of Education (DOE) was sued by wheelchair-bound middle school English teacher Dayniah Manderson over accessibility issues at her school. Manderson claimed that for the 15 years she worked for the DOE she was unable to use the bathroom for up to twelve hours at a time since there was no accessible bathroom available to her (Sequeira, 2021). Manderson said that using the bathroom at work is “a basic human right, and it’s dehumanizing when you are not able to use a bathroom at your place of employment” (Sequeira, 2021). Manderson described her long standing issues with the DOE as a “systemic failure” and that there were situations where she did not feel as though she “was being treated like a human.” (Sequeira, 2021). Similar to most people with disabilities, Manderson feels that groups such as the DOE do not support her and are unwilling to allocate the time, money, and space and that they are “only going to protect themselves” (Sequeira, 2021).

In 2019, there was another lawsuit related to accessibility in New York City against the Metropolitan Transportation Authority (MTA). The lawsuit was filed when MTA did renovations on the subway system and installed new staircases at Broadway Junction without installing elevators as well. The plaintiffs argued this was particularly egregious since it prevented people with disabilities from not only entering or exiting the station, but also using it as a transfer point to the many lines that run through it. One of the plaintiffs, Joe Rappaport, executive director of the Brooklyn Center for the Independence of the Disabled, said that the MTA “has spent millions of dollars without doing the accessibility work” (Brachfeld, 2021). He feels that “they didn’t

think they had to. What they said in response to our lawsuits is, we disagree. But the ADA is pretty clear about this” (Brachfeld, 2021). The MTA once again showed that many government run organizations do not consider people with disabilities in their plans and budgets and only make changes when they are forced to by the law. This case came three years after Bronx Independent Living Services (BILS) sued MTA over not including elevators in their \$21.85 million renovation project at the Middletown Road subway station, also in the Bronx, showing that many organizations are repeat offenders when it comes to not providing accommodations for disabilities (Evelly, 2018).

While many government organizations are unwilling to provide adequate funds for accessibility related projects, private companies are often barriers to inclusivity as well. The ride-hail company Uber recently settled a lawsuit against them with plaintiffs saying they were charged additional fees due to their disability. They were charged with “wait time fees” which were acquired due to the extra time it took them to load their wheelchairs into the vehicle (Bellan, 2022). The assistant attorney general Kristen Clarke of the DOJ’s Civil Rights Division said “People with disabilities should not be made to feel like second-class citizens or punished because of their disability, which is exactly what Uber’s wait-time fee policy did” (Bellan, 2022). She also said that she believes the agreement “sends a strong message that Uber and other ridesharing companies will be held accountable if their services discriminate against people with disabilities.” In a response to the pressure brought by the lawsuit Uber officials said “It has long been our policy to refund wait time fees for riders with a disability when they alerted us that they were charged, and prior to this matter being filed we made changes so that any rider who shares that they have a disability would have wait time fees waived automatically” (Bellan, 2022).

Conclusion

In the United States since 2010, the collective efforts of individuals with physical disabilities, advocacy groups, federal agencies, and societal entities have come together into a campaign aimed at better serving the needs of disabled people. This endeavor takes the form of legislative pursuits, research funding initiatives, and the amplification of disabled voices, challenging current arguments that accommodations are either unnecessary or prohibitively expensive. The issues that people with disabilities face are indicative of a much larger social problem. The needs of people in our society to function in everyday life are oftentimes not being met, even though the solutions might exist and be easily attainable. Whether it be a wheelchair ramp into a building, or public information offered in other languages, the struggles of many could be easily eliminated. If most of these issues are fixable, why do they still exist? The majority of people in our society, and the vast majority of people in power, do not fall into groups that need accommodations and an out of sight, out of mind effect takes place. Most people do not push open a heavy door and think “that would have been impossible to open if I was in a wheelchair, someone should do something about that”. That is why advocacy groups are important in solving these issues, by reminding people that they exist. Still, even when people advocate for marginalized groups, they are often told “no”. Until society as a whole prioritizes people over financial and personal gain, these problems will persist.

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