FIELD REVIEW

Who’s in Charge? Information Technology and Disability Justice in the United States

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ABSTRACT

Disabled people in the United States are surrounded, defined, and, to some degree, controlled by data, technology, and information—from medical technology and therapies to educational systems to social and government services and policies that shape their lives. The extent to which they can access and use technologies to accomplish their own goals is less clear. This review discusses access to data and technology for people with disabilities, focusing on agency and digital transinstitutionalization—the extension of institutional frameworks, such as surveillance and control, from state hospitals into community settings via data-driven technologies. We amplify academic scholarship and public discussion on disability access and accessibility. We also challenge the idea that disabled people have “access” to technology in contexts where they do not control technology, such as healthcare, internet-enabled smart homes and communities, and the workplace. Whenever possible, we highlight the work of openly disabled researchers, authors, thinkers, and advocates across multiple fields who write about disability and technology and work toward equity for disabled people.

“I want to know—raising hands—who are in control. Are you in control? Are staff in control? . . . who’s in charge over you. Are you in charge? Is staff in charge? But who’s in charge?” (R. Johnson and Williams 1999)

Roland Johnson, quoted above, was a leader of the self-advocacy movement for people with cognitive disabilities in the United States [1]. Johnson survived abusive and isolating conditions in Pennhurst State School and Hospital in Pennsylvania during the 1950s and 1960s. Despite finding community housing in the 1970s, Johnson recognized that carceral institutional logics—based on control, surveillance, and punishment—shaped resident and inpatient facilities for disabled people and persisted in community spaces. Even as the United States began closing now-notorious state schools and hospitals for the mentally ill and disabled, such as Pennhurst, Willowbrook, and Danvers, which were widely known to abuse residents (Ben-Moshe 2020; Castellani 1996), the new placements of former residents exercised their own forms of control and abuse. Deinstitutionalization changed the shape of these institutions but not the social and spatial structures framing disabled people's lives (Soja 1980). Technologies reproduced many of the same social dynamics in distributed community settings (Ben-Moshe 2020; Haley and Jones 2020). Johnson, who was eventually elected president of the Philadelphia chapter of self-advocacy organization Speaking for Ourselves in 1986, focused his advocacy on empowering people with disabilities to demand control over their own lives. Like many other disability advocates, Johnson was concerned about how easy it was to take a person out of an institution and pretend that that was enough to call a person free.

The scope and definitions of technology, information, and data are debated at length across many fields. Because we are interested in practical impacts on disabled people, we go beyond technology as *thing*, physical tool, or possession to include definitions of technology as a means for accomplishing goals, including institutional policies and social practices, or "customs of manipulating the physical world" (Bleed 2008, 97), and the materials, media, and tools (such as computers, algorithms, or social media platforms) we use to enact these manipulations. Knowledge, data, and information are entangled components of technologies, embedded with social values and used to achieve connected goals (Bleed 2008). Using technologies to entangle matter and meaning (Barad 2006)—to manifest our beliefs and desires, to shape boundaries in physical space—is an exercise in power. That said, users are not treated equally, and not every use of modern technologies such as computers, machine learning algorithms, the internet, or medical imaging technology shows a user's desires. Therefore, addressing the question of technology access requires an examination of power and what it means to use technology.

To that end, the question of disabled people's "access" to technology, while important as a measure of economic equity, misses the point somewhat. The more useful question is whether and how disabled people can use the technology they want to achieve their goals or whether they are primarily subject to technology as inputs (sources of data), passive subjects for designers and institutions. Can disabled people be called "users" or said to "have access" to technology if they are regularly denied agency over how they use technology? The story of technology and disability in the United States is complex, with innovation and growth consistently intertwined with struggles for basic access and accessibility (Ginsburg and Rapp 2017), systemic bias and ableist [2] assumptions about decision-making (Arstein-Kerslake et al. 2017; Whittaker et al. 2019), surveillance and necrocapitalism [3] (Banerjee 2008; McRuer 2018), and eugenics, colonialism, and racism (Dolmage 2018). Many technologies distribute and hide systems that disenfranchise and control disabled people, denying them full rights of citizenship through institutionalization, coercion, and subjugation.

In this review, we discuss disabled people's relationship to technology, citizenship, and design. We highlight academic scholarship and public discussions on these issues in the United States.

Photo by Ron Lach

Technologically Mediated Identities

Disability, like other facets of identity, is at least partially dependent on socially and technologically mediated categories and interpellations; we are disabled as much by the sociotechnical systems designed to label disability (e.g., medical algorithms and machinery, educational standards and testing systems, and social norms) as our experiences, embodiments, and communities (Butler 1993; Ebert 1996; Ginsburg and Rapp 2020). Several researchers have tried to understand disability beyond the medical paradigm, which frames disability primarily as an outcome of individual physical, emotional, or mental impairments to be accommodated or cured (Altman 2001; Gibson, Bowen, and Hanson 2021; Goodley 2017; Kafer 2013; Oliver 1990). In this review, we also include anyone disenfranchised or disempowered by a technology based on an aspect of their biological, physical, sensorial, or cognitive embodiment. This definition combines social, political, physical, ecological, and technological characteristics of disability, highlighting how the very definitions of disability, race, sex, gender, and sexuality have historically marked particular types of bodies and minds as suboptimal, deserving of diminished rights, and needing greater supervision (Ferri and Connor 2005; Ineese-Nash 2020; Minich 2014). At various points in US history, blood quantum laws, Jim Crow laws, and eugenic classification systems have defined Native, Black, non-Anglo-Saxon immigrants, and white disabled people as intrinsically inferior to nondisabled white people (Dolmage 2018; Kevles 1999). Ethnic, cultural, and economic criteria, such as blood quantum, bone structure, and reading ability, have been used to justify discriminatory practices and disparities in legal rights, healthcare, and educational access.

We also acknowledge the communal nature of disability. Many people who can identify as “disabled” choose not to do so, but many others identify with a shared experience of disability, forming community, connections, and coalition from societally mediated “disablement” (Oliver 1990; Patterson 2018; Sins Invalid 2019). The disability rights and disability justice movements have different approaches to defining the disability community and to addressing the collective needs and experiences of disabled people. The disability rights movement focuses its activism on establishing and expanding civil rights through policy and legislation, such as the Americans with Disabilities Act of 1990 and 2008, Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act of 1990 and 2004 (Patterson 2018). The movement has been criticized for its singular focus on issues and remedies relevant to white, cisgender, heterosexual disabled US citizens and people with mobility issues (Sins Invalid 2019). The disability justice movement expands on this groundwork, prioritizing the experiences, needs, and leadership of disabled people of color, queer, undocumented, and poor disabled people—many of whom have limited access to the legal resources and protections won by the rights movement. Our discussion is based on the intersectional cross-movement work of Sins Invalid (2019), an activist collective widely acknowledged as expressing the core guiding principles of the disability justice movement in the United States.

Legally Disabled

The federal government has no single definition of disability, but US law frames disability as a range of substantial physical, mental, or emotional limitations, usually contrasted with a standardized “normal” (nondisabled) level of function (US Department of Justice Civil Rights Division 2017). Other definitions of disability focus on austerity and fraud prevention, limiting government and insurance spending on people with disabilities (Deal 2003; Rose 2017). Although these rules seem to focus on responsible stewardship of limited resources, they rely on outdated financial models and ableist understandings of disabled people’s lives and work. For example, the Social Security Administration requires that people with disabilities “must not be able to engage in any substantial gainful activity” to qualify for disability support (Social Security Administration 2020). Strict asset limits prevent disabled individuals who need Supplemental Security Income (or Medicaid, in many states) from paid employment, from building enough resources to purchase high-cost items (such as technology), and even from marrying (Altiraifi 2020; Musumeci and Orgera 2021; Perry 2021; Wong 2017). Yet, as Virginia Eubanks (2017) describes, limited access to networked devices for online management of disability benefits can mean sudden and tragic loss of eligibility and services.

In the United States, the poverty rate for noninstitutionalized people with disabilities has been more than double that of nondisabled peers since 2008, with 25.9 percent of disabled people and 11.4 percent of nondisabled people living in poverty (Paul, Rafal and Houtenville 2020). Similar gaps exist in education, with 16.1 percent of people with disabilities having a bachelor’s degree or more, compared with 23.1 percent of nondisabled people. These disparities can feed into a cycle of poverty, exacerbating health problems, limiting access to much-needed resources, and lowering quality of life.

Intersectional Ableism and Multiple Marginalizations

Ableism has long been entangled with other forms of discrimination against bodies and minds considered “less than ideal” (Annamma, Connor, and Ferri 2013; Bailey and Mobley 2019; Benjamin 2019; Glencross et al. 2021). Even so, disability and accessibility researchers and advocates have often overlooked the experiences of disabled people who are multiply marginalized, such as those who are also Black, Latine/x, Indigenous, Asian, poor and/or working class, unhoused, queer, and immigrants. They experience intersecting inequities and unique barriers. Academic, political, and technology spaces that focus on disability also replicate structures of systemic discrimination through a one-dimensional view of disability, regularly privileging white, abled perspectives over others and resisting examination of intersectional ableism (Disability Intersectionality Summit 2017; Gillborn 2015; Leonardo and Broderick 2011). Imani Barbarin's (2020) statement that "the erasure of black, indigenous, and disabled people of color is rampant even despite the ardent calls for inclusion from the disability community at large" builds on Kimberlé Crenshaw's (1989) scholarship on intersectionality. The overwhelming whiteness of the tech industry, media, and academia perpetuates this problem, even as we pay more attention to disability and access. Indeed, as disability activist Vilissa Thompson (Disability Intersectionality Summit 2017) notes, even leadership in disability organizations is disproportionately white, resulting in the disenfranchisement of disabled people of color within movements that represent them.

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Besides replicating systemic racism, this "speaking for" and "speaking over" disabled people of color also limits technological innovation and access. Leah Lakshmi Piepzna-Samarasinha (2018, 72) describes disability justice as centering the "lives, needs, and organizing strategies of disabled queer and trans and/or Black and brown people marginalized from mainstream disability rights organizing's white-dominated, single-issue focus." (Piepzna-Samarasinha 2018, 15). This ingenuity often results in simple innovations that are more widely usable and more focused on collective care and everyday access rather than the production of less accessible computing equipment and cutting-edge technology. Twitter hashtags such as #DisabilityHacks and #SpoonieHacks showcase hundreds of such innovations of a range of applications, from shower accessibility to mask modifications. Similarly, Nicole Ineese-Nash (2020) describes Anishinaabe perspectives on disability as grounded in community, relationships, and development of children's individual gifts. From these community-based perspectives, innovation and access are organized around community care, mutual aid, resource sharing, and networked support systems.

The Covid-19 pandemic has highlighted differences in technology access among disabled people. Many of the structural and social determinants of health and fundamental causes of disease (Braveman and Gottlieb 2014; Riley 2020) that make disabled people of color more vulnerable to disease also fuel digital divides and limit access to information, data, and technology (Dobransky and Hargittai 2006; Estacio, Whittle, and Protheroe 2017; Jaeger 2011; Scanlan 2021). The Pew Research Center found that disabled Americans of all ages are more likely than nondisabled peers to say they never use the internet or do not own a personal computing device of any kind. Technology use differs by race, income, and age groups, with Black and Latine/x people using a more limited range of personal devices to access the internet

(Anderson and Perrin 2017; Perrin and Atske 2021). Eric T. Roberts and Ateev Mehrotra (2020) found that 41.4 percent of Medicare beneficiaries have had no access to a computer or high-speed internet at home during the Covid-19 pandemic, with the percentage rising among people with lower incomes. This has meant more difficulties using telehealth; participating in online education, telecommuting, and online shopping; and using other internet-based services intended to help limit the spread of disease (Scanlan 2021). This is especially dangerous for disabled people who have higher risks both for contracting Covid-19 and for complications and death (Chakraborty 2021; Pineda and Corburn 2020).

Citizenship and the Right to Access

The Right to Public Information and Technologies

Discussions on access to information, data, and technology in the United States are often built on assumptions about the responsibilities and benefits of citizenship, with “productive” civic participation justifying public access to public information, data, and technology (Erevelles 2011; Gibson, Bowen, and Hanson 2021; Minich 2014). This idea of citizenship maps economic privilege, “intelligence,” and education onto definitions of digital and data literacy expecting that good digital citizens are critical thinkers, decision makers, and ethically grounded, fulfilling civic duties such as voting and consuming goods (Choi, Glassman, and Cristol 2017). Full citizens can claim ownership of public space, data, and technology—an example of the practices of respect (Meyer 2000) exercised toward those deemed rational and productive. For example, investment in open government data is justified by the belief that it “increases citizen participation in government, creates opportunities for economic development, and informs decision making” (US General Services Administration n.d.). In contrast, disabled people’s rights to information as citizens are limited by access barriers and policies that prioritize the needs and practices of disabled people’s guardians and care providers over themselves. As such, disabled people regularly use technologies but are often not considered as *users* in design and policy because of the belief that they “cannot be agents with rights but only objects of natural forces, protected and conserved perhaps, but with no voice or will of their own” (Meyer 2000, 6).

> *People with disabilities [are often forced] trade their right to keep personal health information private in exchange for access to public life.*

We see evidence of this rationale in the design of many public spaces and information systems. Inaccessibility of government data and technologies is one example of this marginalization. Audio-only election information, complex ballot design, poorly designed accessibility features on voting machines, and physical barriers make the task of voting independently and privately almost impossible for many disabled people (Lazar, Wentz, and Winckler 2017; Lord 2017). Forced intimacy or the pervasive expectation of personal disclosures about their bodies and health to nondisabled gatekeepers in exchange for accommodations and accessibility (Goggin and Newell 2003; Mingus 2017) is another example. In practice, this might look like a disabled person having to explain why they need captions or having to request an elevator key to access a public space. This common (and frequent) expectation compels people with disabilities to trade their right to keep personal health information private in exchange for access to public life.

Digital Transinstitutionalization, Incarceration, and Surveillance

Joseph P. Morrissey and Howard H. Goldman (1986) coined the term “transinstitutionalization” to describe systems that remove bodies from formal institutions and place them in settings that, though unrecognizable as state hospitals, still embody the institution through less concrete forms of surveillance, discipline, and control. Information infrastructures and digital technologies can reproduce digital transinstitutionalization by embedding carceral technologies into housing, education, voting, and healthcare systems used by disabled people (Haley and Temple Jones 2020). Inaccessible voting booths, jails, ankle monitors, home security systems, and “developmental living facilities” all accomplish the same function: monitoring disabled people under a constellation of technologically validated and socially mediated “guardianships” that deprive them of the rights accorded to full citizens, even as they move about in the world (Arstein-Kerslake et al. 2017; Haley and Temple Jones 2020; Van Oort 2019). Instead of individuals with agency and rights, disabled people become objects to be read, classified, and acted upon. Without agency, they become little more than sources of data.

This paternalistic model of disabled person as datapoint rather than as user extends from the clinic into the community as internet-enabled smart home and smart community technologies use bodies as data to serve caretaker, managerial, and governmental interests. In-home technologies to support disabled people typically center caretakers as users, with system designs that focus on threat detection, wandering, and “problem behaviors” (Hilton 2017; Karakostas et al. 2015; Tsujino, Oyama-Higa, and Tanabiki 2006; Yang et al. 2018). Disabled people are forced to relinquish privacy and personal agency to a network of machines devoted to ensuring peace of mind for others (Brand et al. 2020). In-home care, a system of community-based supports intended to liberate disabled people from large institutional settings, has also been threatened by the integration of information technology (IT) as surveillance systems. For example, Electronic Visit Verification technology, which is meant to monitor caretaker compliance, has effectively eliminated the freedom disabled people have for deciding when and where their care takes place (smith 2018). To be reimbursed, providers must check in from a landline telephone in patients’ homes or using a GPS tracker issued to the disabled person. These trackers have been compared to home ankle monitors in that they relay information about the disabled person’s location (and not just when receiving home and community services).

In some US states, transinstitutionalization has meant shifting disabled people from state hospitals and institutions to prisons (Raphael and Stoll 2013; Vallas 2016). The 1999 Olmstead decision supported disabled people’s right to live in communities rather than institutional settings (US Department of Justice Civil Rights Division n.d.). Yet, in 2019, 3.5 percent of people below sixty-four years of age classified as disabled by the US government lived in congregated settings or “institutional group quarters” (including nursing and skilled nursing facilities and adult correctional facilities such as prisons and jails) (Paul, Rafal and Houtenville 2020). This is compared with 0.69 percent of nondisabled people. Disabled scholars and activists have likened congregated settings such as institutions and nursing facilities to incarceration (Ben-Moshe 2016), describing similarly constructed small worlds (Burnett and Jaeger 2008; Chatman 1991) with severely limited rights of consent and denial, limited privacy, and limited (if any) opportunities to *use* technology and information (Arguelles and Ortiz-Luis 2021; Johnson and Bagatell 2017; North Carolina Department of Correction 2012). Smart city discourse has informed the development of smart prisons, which *subject* incarcerated people to more “efficient” surveillance and control using wearable fitness devices, video surveillance, and smart sensors—many of the same digital technologies used to monitor disabled people living in community settings (Holzki 2019; Kaun and Stiernstedt 2020).

Disenfranchisement by Design

In 2013, the Coleman Institute for Cognitive Disabilities drafted a Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access (see Institute for Cognitive Disabilities 2013). The Declaration is part of a public awareness and policy campaign that draws attention to the systematic disenfranchisement of cognitively disabled people from IT systems. Although cognitive disability is also recognized in the Americans with Disabilities Act, in practice it has rarely been supported in accessibility efforts. For those who are able to connect, much of the internet is still inaccessible, despite accessibility being a legal and human right (United Nations Department of Economic and Social Affairs 2006) and over twenty years of guidance on web accessibility from the World Wide Web Consortium (Brewer 2017; World Wide Web Consortium n.d.). In many cases, technological disenfranchisement of people with disabilities and lack of access arises from the belief that disabled people threaten the efficient functioning of the community. The following sections describe specific contexts in which information access and accessibility can be improved.

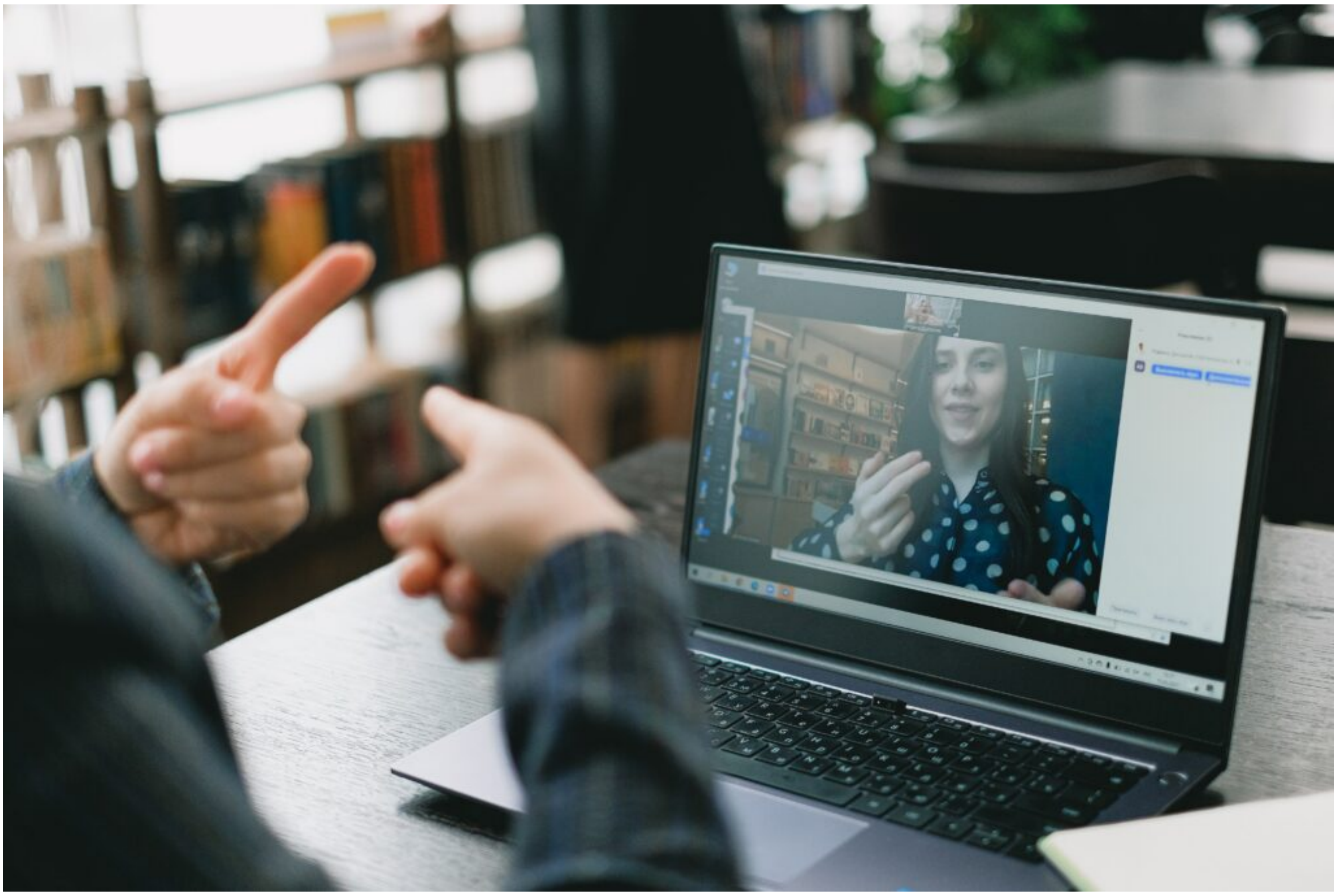

Photo by SHVETS production

Assistive Technology and Disability Dongles

Since 2010, we have seen a push to integrate more disability studies and disability justice perspectives into the study of human-computer interactions and assistive technology (Lundgard, Lee, and Satyanarayan 2019; Mankoff, Hayes, and Kasnitz 2010; smith 2019; Williams and Gilbert 2019) to embrace prefigurative politics [4] (Williams and Boyd 2019). Without understanding the lived experience of disability, the efforts of many nondisabled designers amount to "disability dongles"—a "well intended elegant, yet useless solution to a problem we never knew we had" (Jackson 2019). Traditionally, assistive technology is "aimed at helping persons with disabilities and special education/rehabilitation needs to function better within their daily context and achieve a higher quality of life" (Lancioni et al. 2014, 1). Much of the discourse on innovation around assistive technology focuses on effectiveness and the promise of empowerment (Alper 2019; Ravneberg and Söderström 2018), with cost, awareness, and inadequate assessment being consistent barriers to access (Boot et al. 2018). The disability dongle discussion highlights technological determinism, access doctrines (Greene 2021), and other versions of the belief that new technological "innovations" and skills can fix complicated, long-standing social problems. Emphasizing expensive new assistive technologies over social inclusion and (often cheaper) universal accommodations shifts the collective responsibility for disability inclusion to individual consumers, many of whom cannot afford them.

Technology in Clinical Settings

While advances in medical technology continue to offer improvements to quality of life for disabled people who can access healthcare, the social, racial, and economic politics of disablement and the sociotechnical disenfranchisement of disabled people are perhaps most evident in healthcare settings and systems (De Paor and Blanck 2016; Ledford 2019). In US healthcare systems, the agency of disabled patients is frequently subsumed under the wishes of relatives, expertise of healthcare professionals, and financial interests of clinical organizations and insurance providers. Although many new medical technologies offer life-saving possibilities for those who can access them, they also reinforce and legitimize these hierarchies, prioritizing the wishes of nondisabled relatives, caretakers and providers, through continuous automated monitoring and data collection (Chung et al. 2011; Egger et al. 2019), diagnostic detection (Kunz et al. 2017; Mantri et al. 2015), and, increasingly, algorithmic decision-making (Grote and Berens 2020; Obermeyer et al. 2019; Williams et al. 2021). Patients with disabilities (especially those with cognitive and intellectual disabilities) are frequently deemed incompetent and become sources of data that empower *other* people (e.g., physicians or family members) to make choices that shape their lives and health, often without their knowledge, consent, or power to contest.

> *Algorithmic decision-making based on profitability and potential for cure threatens disabled and chronically ill people's lives.*

Tressie McMillan Cottom's description of *structural incompetence* in healthcare—the assumption that Black people "cannot know ourselves in a way that the context will render legible, or that prompts people with power to respond to us as agentic beings" (McMillan Cottom 2019, 86)—mirrors the experiences of many visibly and intellectually disabled people. The primacy of cure as a goal and value betrays an ableism that labels disabled and chronically ill people as aberrant, expensive, and essentially "noncompliant" (Allen and Kupzyk 2016; Clare 2017) with technologies and policies that rely on sameness to function efficiently. In such a system, a person who will not be cured is a problem. Algorithmic decision-making based on profitability and potential for cure threatens disabled and chronically ill people's lives, as physicians increasingly rely on discriminatory algorithms for diagnoses, and insurance companies choose to overrule physicians' decisions through insurance denials (Ning et al. 2019; Saxena et al. 2020; Swauger 2020). As one example, disabled rights and justice activists still mourn the loss of Carrie Ann Lucas, who died in February 2019 after a year-long battle with sepsis caused when her insurance provider refused to pay for a specific antibiotic (Lucas 2018; Seaman 2019). Appealing insurance denials requires knowledge, time, and resources, and even if they survive the initial denial, disabled people are often forced into a cascading series of medical crises that cost substantially more than the original treatment.

Recommendations

The IT systems we have described all systematically fail to consider the disabled person as a primary user, capable and deserving of full access to the discretionary power those systems are built to afford. As Roland Johnson asks, “Who’s in charge?” IT policy and practice resoundingly answer, “Not you.” With this review, we hope to contest the naturalization of disabled people as data-not-user and make the following recommendations for information and technology imagined differently.

- **Consider disabled people as agential, “independent” system users and build systems for networks of support**. In the words of disabled activist Cal Montgomery, “By ‘independence’ I do not mean what nondisabled people tend to mean, doing things unassisted, but rather doing things uncontrolled. Doing things, with support . . . but without that support being used to control us” (Montgomery 2017).
- **Divest from eugenic and carceral systems that result in disenfranchisement, institutionalization, death, and other harm to disabled people.** Artificial scarcity in education, healthcare, housing, financial support and benefits, and social support results in the exclusion of disabled people from educational, political, and social systems and structures.
- **Give power to patients**. Ensure that decisions about medical care (including decisions about what treatments are medically necessary) are made mutually between patients and healthcare providers, that technologies and data that support decision-making are legible to patients, and that supported decision-making (Arstein-Kerslake et al. 2017; Center for Public Representation 2021) is the default when capacity for decision-making is in question. Insurance companies should not have the power to contest a doctor’s determination of medical necessity.
- **Make the internet a public utility.** The Covid-19 pandemic has highlighted that effective and ubiquitous access to the internet is an essential public service, the denial of which disproportionately disenfranchises disabled, racialized, and poor people from our networked society.

Conflicting discourses around disabled people’s capacity for self-determination have shaped IT policy, particularly through constrained medicalized and charity-based models of research related to technology and disability. IT researchers and policy makers should operate from a baseline assumption that disabled people have full capacity for autonomous decision-making, but that this capacity may be withheld or constrained by power imbalances in the person’s life, not diminished as an inherent trait of their disabled embodiment. In practice, this means centering policy and technology designs on disabled people as fully agential users, rather than assuming the target user is someone with discretionary power over the disabled person. We call on IT policy to shift away from assuming institutional staff, family, and care workers are the data consumer or system user, remembering Roland Johnson’s “Who’s in charge?” and that the answer should always be the disabled person.

Recommended Readings

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Footnotes

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1 We use the terms “disabled people” (identity-first) and “people with disabilities” (people-first) interchangeably in recognition of the varied uses and preferences among different individuals and disability communities (Brown 2017; Dunn and Andrews 2015)

2 Ableism refers to prejudice or discrimination against disabled people (Whittaker et al. 2019).

3 Necrocapitalism refers to economic systems and activities that rely on subjugation and death to generate profit (e.g., economic systems that rely on slavery or prison labor, or the use of war to stimulate economic growth).

4 Leah Lakshmi Piepzna-Samarasinha defines prefigurative politics as “imagining and building the world we want to see now” (2018, 149).

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