JUST
TECH

FIELD REVIEW

Un/Just Care: Imagining the History (and Future) of Disability, Technology, and Care

By: David Adelman

DISCO

Adelman, David. "Un/Just Care: Imagining the History (and Future) of Disability, Technology, and Care." Just Tech. Social Science Research Council. October 11, 2023. DOI: https://doi.org/10.35650/JT.3061.d.2023.

ABSTRACT

Taking the supposed "end" of Covid-19 as a starting point, this field review is an examination of technobureaucracies of care. Bureaucracy, the management of bodies from afar, has become essential to the ebb and flow of modern life, even as it remains perniciously invisible. As a corrective to this, and building on the work of critical disability studies, alongside a feminist ethic of care, I center disability within technobureaucracies of care. I argue that the move to evacuate disability technologies out of history and to remove disability and its technologies from the public eye is both a deliberate rhetorical strategy and a consequence of the established infrastructures of care in the United States. Further, that I center disability, its technologies, and its history is both an autoethnographic impulse as a significantly disabled person—and a commitment rendering the messiness of care and its aftereffects, visible. Finally, drawing from the work of disability activism, I invite the reader to reimagine their own relationship to care and crisis, and to imagine different, more equitable, futures together.

Keywords: Disability; Care; Bureaucracy; Embodied Experiences; Inequality

As of May 21, 2023, the US government has declared the "emergency phase" of the coronavirus pandemic over, following the lead of the World Health Organization's (WHO) announcement on May 5(Kupferschmidt and Wadman 2023). This supposed "end" rings somewhat hollow, however, as people continue to die each week, with some models estimating that excess mortality is still at about 10,000 deaths a day worldwide, the majority of those occurring in individuals age 65 and older—or the most vulnerable and least protected citizens (Kupferschmidt and Wadman 2023). These numbers do not even address the racial and socioeconomic disparities in the United States—wherein Black and Hispanic populations are more likely to experience hospitalization and/or death from Covid-19 due to a variety of factors, as has been widely reported (Clay et al. 2021). Given the still deadly nature of this virus for at least a portion of society, and the ever-present specter of Covid surges, we must acknowledge that attempts to move "beyond" Covid-19 is not about public health policy and community safety.

This is especially true given that public health agencies have long recognized that health itself is in part socially determined. The Centers for Disease Control and Prevention (CDC) notes that "the conditions in which people are born, live, learn, work, play, worship, and age affect a wide range of health, functioning, and quality-of-life outcomes and risks" (National Center for Health Statistics 2016). In short, health is a complicated subject that cannot be flattened to personal responsibility and individual choices, even as the public declarations announcing the end of Covid suggest a resurgence of these logics and an extension of national mythmaking.

> *Heralding the "end" of Covid-19 also works to draw so-called productive bodies back into a neoliberal system of extractive profit, and that this economic imperative deeply colors our technological, legislative, and cultural imagination, because a "[return] to [normal]" is insidious.*

In this sense, a desire to move beyond the pandemic—to "return to normal"—is a nostalgic call for a status quo of some mythologized past, which privileges the able, economically stable, white body—borrowing from Richard Dyer, the "unmarked" (1997, 2) person—and the awareness that whiteness, as a category, is taken to be the default in society. At the same time, heralding the "end" of Covid-19 also works to draw so-called productive bodies back into a neoliberal system of extractive profit, and that this economic imperative deeply colors our technological, legislative, and cultural imagination, because a "[return] to [normal]" is insidious. It suggests that economic crisis is not the status quo, when indeed crisis may be the bedrock of global capitalism, insofar as it is an expected, accounted for, phenomenon—in this sense, exceedingly normal (Fulcher 2015).

If by "normal" we mean the status quo under which economic inequity is not blatantly obvious, then we have not returned to normal. Perhaps that is a good thing, because it surfaces that disabled people, displaced people, and other precarious populations exist. In the crudest sense, the systems in place do not work, even for the people they are designed to "help." Yet, the vigorous cacophony of all those who are not now, (and never were) normal, continue to fight and dream their way to different futures.

Here, I explore the people, practices, and politics that emerge in, and are brought into stark relief by, our current systems of care, ideology, and technology—or technobureaucracy of care. I refer to *bureaucracies of care* and *technobureaucracies of care* interchangeably. In this sense, I posit bureaucracy itself, and the Taylorism that undergird it, as a technology, insofar as bureaucracy refers to systemic hierarchies of management that result in the classification and deployment of human, social, and technological capital that regulates our sociotechnical surroundings. Taylorism, in turn, is a system of scientific management that emphasizes efficiency and profit above all (Hartzband and Groopman

2016). We will move through healthcare bureaucracies and disability technologies, as well as their dense overlaps—all to imagine our present and future differently. These concerns extend before and beyond Covid-19, and yet, it is dangerously naïve to suggest that we might perform a postmortem on Covid-19, epistemologically or otherwise, because people are still dying.

The strange bureaucratic context that Covid-19 illuminates for us is useful—where life proceeds apace as certain vulnerable populations are left behind, or worse. Where the sociotechnical imagination determines that disabled patients are less deserving of medical intervention, because they are less "productive" (Williams, Smarr, Prioleau, and Gilbert 2022). To be clear, this has always happened. Covid-19 has simply revealed some of these processes. What would it mean to center not just individuals, but the communities they occupy, over the status quo? What does it mean to equitably include individuals in public discussions of technology and care, and to teach our students "not to build violent machines"? (Williams, Smarr, Prioleau, and Gilbert 2022)

These questions have no prescriptive answers. I invite us to imagine them together. As Patricia Bernes writes, "dreaming is a matter of survival" (Kafai 2021, 11). Pulling from Bernes, one of the founders of the disability justice (DJ) movement, is intentional. DJ is an intersectional, activist movement led by queer of color and trans disabled people that seeks to capacitate those most marginalized and in crisis (Kafai 2021, 11). Importantly, "dreaming" here is meant in its thickest, most evocative sense. As Leah Lakshmi Piepzna-Samarasinha writes, "dreaming is not about 'not letting disability define you!' It is about making disabled homes, disabled kinship networks, disabled ways of loving, fighting, and organizing that not even the most talented ableds could dream up in a million years" (2022, 156). Building on this, I write from the viewpoint that disability culture and knowledge can speak to scientific and technological concerns, even as disabled people have been historically ignored, abandoned, or deemed useless.

Not incidentally, this focus also emerges from my perspective as a physically disabled man with cerebral palsy who uses a wheelchair and is dependent on personal care attendant (PCA) services to work and live. These are spaces and technologies with which I have intimate familiarity and frustration. As a researcher, I know writing about care bureaucracy often tends toward the abstract, the banal, and the deliberately obtuse. I have attempted to avoid that here. Instead, offering a more careful approach. This is a probing of our assumptions about care, who we should care for, and why. It is designed to invite you, the reader, to reflect on your relationship to care, whatever that may be.

> *Care as we know and experience it is often imagined as a finite good, something that can be exhausted, not a fundamental aspect of the worlds we inhabit.*

We are surrounded by infrastructures of care and its lack, even for the physically and mentally "fit" among us. In the United States, care is increasingly delivered through bureaucratic means—in nursing homes and assisted living centers; through insurance policy and regulation; even in private homes and apartments, for those of us lucky enough to be able to afford them. Crucially, bearing in mind that care, as it is practiced historically and in our present moment, is not always kind. It can be violent, even downright malignant. Care as we know and experience it is often imagined as a finite good, something that can be exhausted, not a fundamental aspect of the worlds we inhabit. This is the specter of the "trolley problem" that permeates so much scientific and technological discourse—that for some to live, some must *necessarily, logically,* die. This project is an effort to imagine care not as a good, but series of possible orientations, inflected by the imbrication of history, power, and culture. This is an opportunity to pull, push, and grapple with bureaucracies of care across contexts. To begin, I examine "need," scarcity, and disability as unwanted burden, all fundamental animus behind bureaucratic care and the management of bodies.

Orientation I: Needy Bodies and Parasitical Care

Tobin Siebers notes that disabled people are uniquely marked in the United States as "a small but needy group that requires more resources than it deserves" (2001, 748)—suggesting another rationale for why disabled people are not centered in the decision to "move on" from Covid-19. Furthermore, the portrayal of disabled people as "resource hungry" fundamentally colors policy interventions. That is, this messaging is used to justify a lack of political change and movement, and as a result, legislation around care and labor has years-long implementation periods. For instance, Section 1 2006(a) of the 21st Century Cures Act,

> Requires all states to implement Electronic Visit Verification (EVV) for Medicaid personal care and home health care services. The Cures Act requires states to implement EVV by January 1, 2020, for personal care services and by January 1, 2023, for home health care services. Failure to meet these deadlines puts states at risk of losing federal Medicaid matching dollars ("21st Century Cures Act" n.d.).

As of this writing, Michigan, the state where I currently reside, has requested an exemption to this implementation requirement from the Centers for Medicare and Medicaid Services (CMS). CMS has granted this extension until January 1, 2024. As of yet, the state has not implemented EVV requirements. Ostensibly, EVV increases the visibility of workers in the home and reduces Medicaid fraud—in this case, a reduction in the frequency of individuals claiming pay for hours they did not work. In truth, such systems are not fraud proof, and in fact, the primary result of this legislation has been a further transformation of the caregiver into the worker. Importantly, this transformation is deliberate. As sociologist Akemi Nishida notes, care formations in the community support the status quo. In this case, the status quo is a system of extractive neoliberal labor (2022, 17) that puts disabled people against caregivers-as-workers to diffuse any challenges to this status quo, even as EVV also places disabled people under more electronic surveillance, since some EVV systems can collect audio and visual data in addition to biometrics (Scalia 2019). This technological innovation creates a profit-seeking industry that uses the insinuation of fraud to create a sense of necessity, urgency, and logic for their interventions. Moreover, the transformation of caregiver into worker also transforms the home into a workplace. The collision and elision of public and private spaces has long been favored territory of queer theory as well as disability studies, and panic over public intrusion into private spaces also has ongoing political resonance. Thus, disabled people often find themselves surveilled subjects even in so-called private spaces.

Additionally, even as the US government would like to tighten control over the implementation and deployment of healthcare on a larger scale, disability is problematic. It resists bureaucracy—and efficiency—even as the state increasingly turns to bureaucracy as a solution. To borrow Bowker and Star's schema, disability is a messy classification (1999). It frustrates bureaucracy, because so often disability extends beyond easy binaries. In the United States, an exemplary case of this is Supplemental Security Income (SSI) administered by the Social Security Administration (SSA). For the purposes of SSI, the SSA defines disability as having a medical condition that, among other things, "prevents the individual from [doing work]" (Whittle et al. 2017, 182). Here, "doing work" is understood to mean receiving gross yearly income above a certain level. If an individual does receive an income above this level, they are not considered to be disabled, making them ineligible for SSI. In addition, Medicaid, the other major government healthcare insurance, also uses income and asset limits. These bureaucratic litmus tests often disregard the embodied nature of disability. That is, regardless of my income level, I will always need a wheelchair. I will always need someone to help me into and out of bed, as I have no capacity to stand independently, to undress myself, to shower myself, and so forth. In a bureaucratic, neoliberal understanding of disability, the government is not responsible for social welfare, and yet, social welfare programs like Medicaid and SSI are often the only programs designed to explicitly address disabled people's needs in the United States—as far as providing ongoing, continuing, in-home PCA services. Against the backdrop of bureaucratic care, Nishida offers "just care":

> Just care occurs when people feel cared for affirmatively, whether they are situated as care workers, care receivers, or both, and when care is used to improve the well-being of people, the community, and the surrounding (i.e., natural and built) environment, and for more-just world-building (2022, 7).

Nishida’s understanding of care is useful for a variety of reasons. Perhaps most explicitly, for Nishida, as well as others writing toward a feminist ethic of care, care is not unidirectional; it is relational.

Feminist theory has long been concerned with questions of care and/as labor due to the overwhelmingly gendered and racialized nature of care expectations (see Tronto 1993). Crucially, one can both be a care receiver and a care giver—which, again, highlights the false distinction between the two. Just care is also built on and emphasizes the notion of affirmative care. This understanding of care foregrounds the importance of mutual support *as well as* the provision of resources to imagining more equal futures. Additionally, just care is not inherently hierarchical—unlike bureaucracies, which are predicated on hierarchies of power and regulation. The United States, in particular, clings to a neoliberal drive, which elevates certain kinds of productivity—to work as many hours as possible with minimal breaks all in the name of profit. This system positions care as a scare commodity, a finite resource dispensed to only the most dependent, needy groups—even though, as the SSA’s own policies demonstrate, disabled people are often forced into impoverished positions due to a narrow understanding of what disability looks like in society and culture. In other words, in bureaucratic regimes of care, disabled people do not contribute as abled bodied people do. Instead, they simply take resources, energy, and labor. Most insidiously in the US context, disabled people must continually “prove” their disability, rooted in regimes of diagnosis and deficiency. This system is always looking for a reason to deny care.

The idea that disability turns productive citizens into parasites who must be managed is at its extreme, bluntly eugenic.

This orientation of care imagines the disabled as useless eaters, and essentially parasitical. This is not uncommon in the larger historical landscape of disability policy, either. Susan Schweik traces the history and construction of the disabled body as the begging body throughout the late nineteenth and early twentieth century (2009). In turn, the idea that disability turns productive citizens into parasites who must be managed is at its extreme, bluntly eugenic. This is what guides my choice to gesture to “useless eaters.” The United States Holocaust Memorial Museum dedicates a page of its Holocaust encyclopedia to the Third Reich’s euthanasia program. They write,

> The Euthanasia Program was the systematic murder of institutionalized patients with disabilities in Germany. … The program was one of many radical eugenic measures which aimed to restore the racial “integrity” of the German nation. It aimed to eliminate what eugenicists and their supporters considered “life unworthy of life”: those individuals who—they believed—because of severe psychiatric, neurological, or physical disabilities represented both a genetic and a financial burden on German society and the state (United States Holocaust Memorial Museum 2020).

In this explanation, the museum focuses its attention on a racist notion of “genetic burden,” but also on the notion that people with physical disabilities are a financial burden. This idea manifests across culture and historical periods. Disability often comes to represent the deviant, the lazy, the parasitical (Deutsch and Nussbaum 2000). Most importantly, Germany’s euthanasia program highlights that care and control are often concomitant with one another. Moreover, this example demonstrates the violence that can pervade care, allowing harm and injury to individuals and groups. Nishida writes that care can be turned into a "mechanism of social oppression and control" (2022, 7). This care/control phenomenon manifests outside of healthcare contexts. Primary schools also endeavor to care for the disabled students in their charge. Yet, we are still left with horrific headlines of "behavior technicians" in Indiana who force their students to consume their own vomit off of a lunch plate as part of life skills instruction (Fradette and Santucci 2023). Though the perpetrators of that instructional method have been publicly castigated and arrested, this example demonstrates the porous nature of care, control, and punishment—in the form of regurgitated bile.

Orientation I ½: Care as Profit Motive

Earlier, I drew on the example of EVV to demonstrate the transformation of caregiver into care worker. This is but one example among many wherein care in capitalism is often driven by profit. Marta Russell, the noted disability activist, wrote in 1998:

> Two thirds of nursing homes are for-profit businesses. Medicaid funds 60 percent, Medicare 15 percent, and private insurance 25 percent. When a single impaired body generates $30,000–$82,000 in annual revenues. Wall Street brokers count that body as an asset, which contributes to a nursing home chain's net worth. Though transfer to nursing homes and similar institutions is almost always involuntary, and though abuse and violation of rights within such facilities is a national scandal, it is a blunt economic fact that, from the point of view of the capitalist "care" industry, disabled people are worth more to the Gross Domestic Product when occupying institutional "beds" than they are in their own homes (2019, 160).

In the time that has passed since 1998, nursing home profits have only increased (Spanko 2019). Still, in recognizing that even while being "warehoused," disabled bodies can produce profit, it adds an additional layer to the crisis of care that occurred early in the pandemic in nursing homes. While the loss of life in nursing homes as a result of overcrowding, labor shortages, and lack of personal protective equipment will always be tragic, it is a direct result of privileging profit over safety. As Michael C. Brannigan notes, during the Covid-19 public health emergency, the Centers for Medicare and Medicaid Services (CMS), waived the 75-hour training requirement for nurse aides in nursing homes, which allowed staff to provide care after just an 8-hour online training program (Brannigan 2022, xv). This blanket waiver remained in place until April 2022. However, in August of that year, new guidance from CMS allowed for waivers of aide training requirements on a facility, state, or county basis (Edelman 2022). Given the recently declared end of the Covid-19 public health emergency, this may also mean the end of training waivers for nursing homes, assisted living centers, and residential care facilities. However, given the prevalence of these temporary nursing aides during the public health emergency, two things are exceedingly likely: (1) We will continue to feel the ramifications of this labor strategy—that is, hiring under qualified individuals ill-equipped for critical and ongoing care situations—as a strain on our already underfunded healthcare systems for years to come; and (2) in the event of another widespread public health emergency, any long-standing health regulations are likely to be jettisoned. Thus, healthcare legislation and regulation are fundamentally porous.

I should note that vis-à-vis healthcare in the United States, the importance of CMS cannot be overstated. They are a central player in healthcare policy, regulation, and implementation. CMS not only provides healthcare in the form of health insurance and PCA services, but also complex disability/medical technology. Through this role, they also mediate many disabled people's ability to interact with society.

As Aimi Hamraie and Kelly Fritsch note in "Crip Technoscience Manifesto," technology is often held up as how the nonnormative body is rehabilitated back into productivity and normality. This is often done by way of a medical and scientific expert, who is able-bodied and is endowed with specialized expertise (2019, 8). In this way, our cultural understanding of disability is inextricably tied to our understanding of technology.

The inherent paradox of disability technology is that it is simultaneously understood to be highly specialized, yet ahistorical. We recognize the wheelchair, for instance, as a ubiquitous symbol of disability; so much so that the wheelchair symbol has been taken across the globe to mean handicapped/accessible. But, outside of some corners of disability studies and design courses, the history of the wheelchair is largely unknown.

Orientation II: Care as Technological Genius

Googling the history of the wheelchair reveals an almost folkloric factoid—wheelchairs have always existed, at least, as far back as the sixteenth century when King Philip II of Spain is recorded as having needed one. That we associate advanced technology with wealth is not surprising. Yet, disability communities have long practiced mutual aid through workshops, community meetings, and the fundraising to provide access to technological resources (Williamson 2019). Disabled people have always tinkered with, repaired, stylized, and fashioned our technological devices—both in the mechanical and the aesthetic sense. In this way, our tools become ourselves. As Nelson, Shaw, and Stevens write, our mobilities, and the possibilities that come with them, shift across technology use (2019). They use the term *transmobility* to articulate the notion that disabled bodies have a vast array of movement options available to them at any given moment, with the appropriate access to technological infrastructure.

In this way, the nonnormative body literally resists being “fixed” and, instead, becomes a medium through which it is possible to experience the world differently. Importantly, disability technology can be pleasurable. Disability is not something to be erased or improved upon through the scientific management of the body and its surroundings, though Taylorism cannot imagine this. In turn, this rich nuance and possibility is often lost in the standard, received histories of technological innovation. This is as true of the wheelchair as anything else. From King Philip II, standard histories chart the next innovation in wheelchair technology to 1950, when, at the behest of the National Research Council of Canada, George Klein invents the first power wheelchair, popularly known as the “Klein chair” (Bourgeois-Doyle 2004, 175).

> *Suggesting that disabled people benefit from a “natural” evolution of humanity disregards or underdetermines the roles of politics and positionality.*

Importantly, this bit of Canadian mythmaking, which posits the invention of the power wheelchair as the inevitable outcome of postwar economic investment, depends on certain kinds of debilitated bodies—paralyzed, male, Canadian World War II veterans. The notion that technological innovation “solves” disability is bolstered by Klein’s own biographer, who writes that “the natural, albeit glacial, evolution of humanity in the treatment of the disabled was magnified in the postwar period by an atmosphere of relative affluence and gratitude” (Bourgeois-Doyle 2004, 164). Suggesting that disabled people benefit from a “natural” evolution of humanity disregards or underdetermines the roles of politics and positionality. In fact, the author also mentions the Canadian Paraplegic Association. That they were intimately involved in the advocacy process that brought about the first power wheelchair, belies the notion that disabled people experience a “natural” progression or evolution in culture and society without external influence.

In addition, the very idea that gains for disabled people happen due to a benevolent society exposes a pernicious belief embedded in our sociotechnical context even to this day. Like its cousin, the myth of the “deserving poor,” the idea of a “deserving” disabled public is equally insidious. It suggests its opposite, the parasitical beggar I illustrated earlier, or the notion that there is a way to be “properly disabled” and, by doing so, upholding the correct social hierarchy. Setting aside the idea of (acquired) disability as a metaphor for national patriotism and noble sacrifice, the idea that the power wheelchair is the result of individual genius is bolstered by the elision of technological infrastructures that benefit the medical industrial complex. For instance, the development of mass production facilities as a result of wartime infrastructure that allows for widespread deployment of the “Klein chair,” which in turn allows for its dominance in the postwar marketplace.

This narrative also erases the embedded knowledges that disabled people bring to their medical technologies and mobility devices. Returning to Bess Williamson, she writes about the ingenuity of paraplegic mothers in the 1950s, who built an array of assistive devices designed to extend their capacity to be productive care givers and spouses, especially in the kitchen and as cooks (2019, 184). Drawing out the submerged history of wheelchairs uncovers other imaginaries for disability technology that center other ways of being in the world and envision other priorities beyond the desire to be made productive, or to “return to normal.”

For instance, it is a long-standing dictum of the disability rights movement that nonambulatory wheelchair users are not “wheelchair bound,” and to suggest that they are is a fundamental misrecognition of the sociotechnical relationship between user and chair. The wheelchair does not bind a user to itself. Rather, the wheelchair becomes an interface that opens up the possibility of social interaction. In the parlance of disability rights, the wheelchair provides access and freedom, expanding the wheelchair user’s life-world in concrete, demonstrable ways.

Of course, the argument that wheelchair users, as well as other disabled people, want to be social is in many ways an ideological one. Disability activism and disability justice collectively argue that the experience of disability is not inherently tragic. Rather, it is simply another way of being in the world and as such, should not limit a disabled person’s ability to interact with and participate in their social and technological environments. Ostensibly, this is also the stated goal of a medical discourse of disability. No doctor or funding institution would explicitly state that disabled people shouldn’t be able to interact with their environment. However, the available funding sources for the technological supports that disabled people rely on to survive and thrive are far more limited in scope.

To understand this disconnect, one must comprehend the more recent history around policies related to power wheelchairs and other mobility devices. In turn, all of this logic works to support regimes of care that reduce disabled people into passive agents of capitalism. This form of care is often epistemologically violent, even if it is not physically so. The Centers for Medicare and Medicaid Services (CMS), as I mentioned above, is one of the major funding sources for complex medical technology in the United States. In 2005, they published an influential bulletin, designed primarily for internal consumption and review, stating that:

> CMS finds that the evidence is adequate to determine that MAE (mobility assistive equipment) is reasonable and necessary for beneficiaries who have a personal mobility deficit sufficient to impair their participation in mobility-related activities of daily living (MRADLs) such as toileting, feeding, dressing, grooming, and bathing in customary locations within the home (Centers for Medicare and Medicaid Services 2005).

In this explanation of benefits, CMS explicitly notes that power wheelchairs are designed to help individuals “within the home,” not in public spaces. The home is the primary site of intervention for rehabilitation. This aligns with Williamson’s gloss of disability technology being designed to create rehabilitative environments inside the home, while also recalling my earlier suggestion that the home has a long history as a distinctly public space for disabled people. Additionally, this is assistance by exclusion. Meaning, to qualify for a power wheelchair, the medical team that serves the applicant—which often includes not just a doctor, but a physical therapist and an assistive technology professional (ATP), an individual credentialed by the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)—must agree that the applicant cannot use a manual wheelchair, specifically that “other mobility aides cannot resolve [a patient’s need]” (Michael, Sytsma, and Cowan 2020, 103). This is a multilayered ecosystem of service that thrives on discourses of professionalization, “expertise” and medical gatekeeping. Furthermore, it presumes from the start that care can and often is denied for purely bureaucratic reasons—for instance, a mismatch between information provided via prescription by a primary care provider, and the documentation generated by the ATP.

This totalizing logic belies the lived experience of disability, where different technology allows for different kinds of access, as I mentioned earlier. Manual wheelchairs are lighter, more portable, and often, more resistant to improper handling, like one might find while air traveling, or traveling in general, where portability and transportability are prized. However, according to these funding guidelines, Medicaid will not pay for both a manual and a power wheelchair, because advocating for one excludes the other. This logic is predicated on a prevalent notion in the United States—that access to healthcare is a privilege, not a right, and that it operates against a condition of scarcity.

Additionally, Medicaid in particular enforces a personal asset limit of not more than $2,000 in a beneficiary's account at any one time, while also enforcing an annual income limit that is approximately commensurate to the federal poverty level guidelines. For 2023, in Michigan, those limits are between $14,000 and $32,000 (American Council on Aging 2023). This number is highly contextual and based on the various programs an individual may qualify for. In any given state, there may be multiple Medicaid programs, and an individual may qualify for some with conflicting financial requirements.

> *To access necessary care support as a disabled person, poverty is enforced.*

Medicaid is essential to many disabled people's capacity to live independently in the community because it is the only insurance in the United States that pays for ongoing, continuous, home healthcare. But Medicaid's financial limits draw a more general point. To access necessary care support as a disabled person, poverty is enforced. This is the very same protocol that governs SSI, so I reiterate my earlier point: This understanding of disability does not account for the embodied nature of disability. Put bluntly, no amount of money will endow a disabled individual with the capacity to toilet themselves, or to walk.

Coda: Imagining Just Worlds

The Merriam-Webster dictionary defines the root of "bureaucracy" as coming to English via the French word *bureaucratie*, which combines the word *bureau* (desk) and *–cratie* (a suffix for government), in other words translated literally to "rule by desks." The allusion to bureaucracy as fundamentally disengaged remains persuasive. Yet, here, I have aimed to demonstrate that understanding, or at the very least grappling with bureaucracies of care, is vital in our "post" Covid-19 moment. Bureaucracies of care, and the Taylorism that subtend it, are not inherently bloodless, dry, and dusty. That they appear so is a deliberate tactic of distraction to prop up the status quo. Care is not only a concern for the chronically ill, disabled, or those otherwise in crisis, even as disability bureaucracy is deliberately opaque and haunted by a disposition to view disabled beneficiaries as fraudulent scammers. The Gordian knot of paperwork and telephone lines forms a bottle neck in an outdated system that cannot view the disabled body as productive *and also* disabled. Such bodies do not exist. Except, I say this, knowing full well we do exist. To live in the neoliberal present and be disabled is nearly impossible. Yet, the rates of disability are only set to grow, whether due to increasing age or the aftershocks of Covid, as one of the largest mass disabling events in recent memory—and it won't be the last.

The only way to survive a pandemic is through mindful, intentional, mutual care. This is not something that emerges reliably like a groundhog or cicada at the mere suggestion of crisis, because we are always already in crisis. Care, as with disability and bureaucracy, has technological nuance and import—what technology itself cannot provide is care. People care for people. In turn, care is perhaps most effective through organizing, which is done through the work of health justice commons, coordinated efforts to distribute personal protective equipment and masks, or online disability support networks centered on disabled experience. In short, collectivity is perhaps a way forward. As I close out this essay, I want to suggest that just care is utopian. It recognizes the world-as-it-is and works to build the world-as-we wish-it-to-be—however frustrating, terrifying, or joyous that might be.

Recommended Readings

Brannigan, Michael C. 2022. *Caregiving, Carebots, and Contagion*. Lanham, MD: Lexington Books.

Kafai, Shayda. 2021. *Crip Kinship: The Disability Justice & Art Activism of Sins Invalid*. Vancouver, BC: Arsenal Pulp Press.

Nishida, Akemi. 2022. *Just Care: Messy Entanglements of Disability, Dependency, and Desire*. Philadelphia: Temple University Press.

Williamson, Bess. 2019. *Accessible America: A History of Disability and Design*. New York: New York University Press.

References

"21st Century Cures Act." n.d. Michigan Department of Health and Human Services. Accessed May 15, 2023. https://www.michigan.gov/mdhhs/assistance-programs/medicaid/portalhome/electronic-visit-verification/electronic-visit-verification-about-evv/21st-century-cures-act.

American Council on Aging. 2023. "Michigan Medicaid Income & Asset Limits for Nursing Homes & In-Home Long-Term Care." Last modified January 25, 2023. https://www.medicaidplanningassistance.org/medicaid-eligibility-michigan/#:~:text=In%202023%2C%20the%20Medically%20Needy,%241%2C643%20%2F%20month%20for%20a%20couple.

Bourgeois-Doyle, Richard I. 2004. *George J. Klein: The Great Inventor*. Ottawa: NRC Press.

Bowker, Geoffrey C., and Susan Leigh Star. 1999. *Sorting Things Out: Classification and its Consequences*. Cambridge, MA: The MIT Press.

Brannigan, Michael C. 2022. *Caregiving, Carebots, and Contagion*. Lanham, MD: Lexington Books.

Centers for Medicare and Medicaid Services. 2005. "Mobility Assistive Equipment (MAE)." Medicare Coverage Database. https://www.cms.gov/medicare-coverage-database/view/ncd.aspx?NCDId=219.

Clay, Shondra Loggins, Markisha J. Woodson, Kathryn Mazurek, and Beverly Antonio. 2021. "Racial

Disparities and COVID-19: Exploring the Relationship Between Race/Ethnicity, Personal Factors, Health Access/Affordability, and Conditions Associated with an Increased Severity of COVID-19." *Race and Social Problems* 13 (4): 279–291. https://doi.org/10.1007/s12552-021-09320-9.

Deutsch, Helen Elizabeth, and Felicity Nussbaum, eds., 2000. *"Defects": Engendering the Modern Body*. Ann Arbor: MI: University of Michigan Press.

Dyer, Richard. 1997. "The Matter of Whiteness." In *White*, 1-40. New York: Routledge.

Edelman, T. 2022. "CMS Authorizes New Waivers of Nurse Aide Training Requirements for Nursing Facilities." Center for Medicare Advocacy, September 1, 2022. https://medicareadvocacy.org/cms-authorizes-new-waivers-of-nurse-aide-training-requirements-for-nursing-facilities/.

Fradette, Rachel, and Jeanine Santucci. 2023. "Indiana Special Education Workers Charged with Felony after They Made Student Eat His Own Vomit." *USA Today*, April 27, 2023. https://www.usatoday.com/story/news/nation/2023/04/26/indiana-special-ed-staff-who-made-student-eat-vomit-charged-police/11747240002/.

Fulcher, James. 2015. "Crisis? What Crisis?" In *Capitalism: A Very Short Introduction*. 2nd ed., 102–126. New York and London: Oxford University Press.

Hamraie, Aimi, and Kelly Fritsch. 2019. "Crip Technoscience Manifesto." *Catalyst: Feminism, Theory, Technoscience* 5 (1): 1–33. https://doi.org/10.28968/cftt.v5i1.29607.

Hartzband, Pamela, and Jerome Groopman. 2016. "Medical Taylorism." *New England Journal of Medicine* 374 (2): 106–108. https://doi.org/10.1056/NEJMp1512402.

Kafai, Shayda. 2021. *Crip Kinship: The Disability Justice & Art Activism of Sins Invalid*. Vancouver, BC: Arsenal Pulp Press.

Kupferschmidt, Kai, and Meredith Wadman. 2023. "End of COVID-19 Emergencies Sparks Debate." *Science* 380 (6645): 566–567. https://doi.org/10.1126/science.adi6511.

Michael, Erin, Terin Sytsma, and Rachel E. Cowan. 2020. "A Primary Care Provider's Guide to Wheelchair Prescription for Persons with Spinal Cord Injury." *Topics in Spinal Cord Injury Rehabilitation* 26 (2): 100–107. https://doi.org/10.46292/sci2602-100.

National Center for Health Statistics. 2016. "Social Determinants of Health." In *Healthy People 2020 Midcourse Review*. Hyattsville, MD: US Department of Health and Human Services. https://www.cdc.gov/nchs/data/hpdata2020/hp2020mcr-c39-sdoh.pdf.

Nelson, Mallory Kay, Ashley Shew, and Bethany Stevens. 2019. "Transmobility: Possibilities in Cyborg

(Cripborg) Bodies.” *Catalyst: Feminism, Theory, Technoscience* 5 (1): 1–20. https://doi.org/10.28968/cftt.v5i1.29617.

Nishida, Akemi. 2022. *Just Care: Messy Entanglements of Disability, Dependency, and Desire*. Philadelphia: Temple University Press.

Piepzna-Samarasinha, Leah L. 2022. *The Future Is Disabled: Prophecies, Love Notes and Mourning Songs*. Vancouver: Arsenal Pulp Press.

Russell, Marta. 2019. “Stuck at the Nursing Home Door.” In *Capitalism and Disability: Selected Essays by Marta Russell*, edited by Keith Rosenthal, 152–163. Chicago: Haymarket Books.

Scalia, Kendra. 2019. “Electronic Visit Verification (EVV) Is Here.” Disability Visibility Project. March 24, 2019. https://disabilityvisibilityproject.com/2019/03/24/electronic-visit-verification-evv-is-here/.

Schweik, Susan M. 2009. *The Ugly Laws: Disability in Public*. The History of Disability Series. New York: New York University.

Siebers, Tobin. 2001. “Disability in Theory: From Social Constructionism to the New Realism of the Body.” *American Literary History* 13 (4): 737–754. https://www.jstor.org/stable/3054594.

Spanko, Alex. 2019. “Medicaid’s Share of Nursing Home Revenue, Resident Days Hits Record High as Medicare Drops to Historic Low.” *Skilled Nursing News*, December 11, 2019. https://skillednursingnews.com/2019/12/medicaids-share-of-nursing-home-revenue-resident-days-hits-record-high-as-medicare-drops-to-historic-low/.

Tronto, Joan C. 1993. *Moral Boundaries: A Political Argument for an Ethic of Care*. Psychology Press.

United States Holocaust Memorial Museum. 2020. “Euthanasia Program and Aktion T4.” Holocaust Encyclopedia. Last modified October 7, 2020. https://encyclopedia.ushmm.org/content/en/article/euthanasia-program.

Whittle, Henry J., Kartika Palar, Nikhil A. Ranadive, Janet M. Turan, Margot Kushel, and Sheri D. Weiser. 2017. “‘The Land of the Sick and the Land of the Healthy’: Disability, Bureaucracy, and Stigma among People Living with Poverty and Chronic Illness in the United States.” *Social Science & Medicine* 190: 181–189. https://doi.org/10.1016/j.socscimed.2017.08.031.

Williams, Rua M., Simone Smarr, Diandra Prioleau, and Juan. E. Gilbert. 2022. “Oh No, Not Another Trolley! On the Need for a Co-Liberative Consciousness in CS Pedagogy.” *IEEE Transactions on Technology and Society* 3 (1): 67–74. https://doi.org/10.1109/TTS.2021.3084913.

Williamson, Bess. 2019. *Accessible America: A History of Disability and Design*. New York: New York University Press.