

From Quality of Life to Disability Justice: Imagining a Post-Covid Future

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By

Like a CT-scan of the American body politic, the COVID-19 crisis has revealed deep fault-lines in our medical system, especially the inequities that stratify health care along lines of race, class, age and disability. In the midst of ongoing devastation, future visions of a more just world that might emerge from this situation include an alternative model advanced by disability bioethicists, whose longstanding policy concerns have been amplified by the epidemic. From nursing home neglect to employment precarity to medical rationing, pandemic conditions put disabled people at considerable risk. In the U.S., when crucial medical equipment is in short supply, everything from access to PPE to ventilators to dialysis machines is entrapped in bureaucratic and often politicized federal, state, and municipal networks struggling to manage the constantly changing profile of a pandemic in process.

In this national conversation, people with disabilities are demanding equitable treatment, a place at the decision-making table, and a right to an accessible future. Never has the foundational slogan of the disability rights movement, “Nothing about us, without us” been more apt and urgent. This movement is not new but is finding newly powerful ways to be heard, challenging “common sense ableism.”^[1] Disability activist networks are using their well-established local and national platforms to express outrage, fear, and determination, insisting on their medical rights in the midst of this pandemic, while also finding creative ways to build community and resilience. As disability scholar and bioethicist Rosemarie Garland Thomson recently queried:

“The objections that are raised in lawsuits that have been filed by disability rights groups and organizations could not have come forward without these ideas and the policies that transformed people with disabilities from medical subjects into political subjects. That it is not just unethical, but also illegal to discriminate against people on the basis of disability has actually mobilized the entire nation to change old guidelines and to remake them to consider more equitably what justice might be. Recognizing our shared vulnerability, then, in this pandemic is not novel or an exception, but rather it’s an opportunity to invigorate our shared national and

global commitment to building together a more equitable and shared world with equality and justice for all.” [2]

At the onset of the pandemic, disability activists challenged the flawed logic of mainstream pundits who proclaimed that only older and disabled people would die from COVID-19, suggesting that younger and nondisabled people need not fear, or contribute to general social precautions. Sunaura Taylor, for one, argues:

“The conditions that make someone more vulnerable to COVID-19 are of course intimately tied up with poverty, environmental racism, and inadequate health care. Thus while such a sentiment is unabashedly ableist—should we mourn the lives of the healthy and robust more than the lives of the ill and disabled?—it is also deeply racialized, a message to America’s white middle class that they have no need to panic.” [3]

Soon thereafter, as healthcare systems were overwhelmed, the rationing of medical support—once unthinkable—became part of public discourse regarding whose care should take priority. Across both red and blue states, the lives of disabled people—as well as older people and those with “pre-existing conditions”—have been discounted in many guidelines for who to prioritize in times of crisis, when medical technologies, personnel, and facilities are overburdened. [4] On March 28, the Federal Office for Civil Rights (OCR) issued a bulletin on *Civil Rights, HIPAA, and the Coronavirus Disease 2019*, asserting:

“Persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities or age.” [5]

Almost immediately, a number of disability legal groups produced expanded nondiscrimination statements, elaborating on the OCR bulletin and offering more detailed standards of care. [6]

These disability justice guidelines insist that rationing is not, in fact, a new problem; it is endemic rather than epidemic to modern medicine under capitalism, whether nationalized or market-based. Physicians have long made similar arguments. In a 1987 piece in *The Lancet*, for instance, David Grimes compared the “explicit” rationing of private health insurance, which applies “exclusions such as psychiatric illness, pregnancy, neonatal intensive care, long-stay care of the elderly, and

alcohol-related disease” in determining coverage, to the “implicit” rationing of the U.K.’s National Health Service plan, which sets treatment rates and workloads for certain procedures using the Quality-Adjusted Life Years (QALY) metric.^[7] Current U.S. governmental plans for medical resource allocation have roots in everyday health economics (e.g. QALYs as well as Quality of Life indexes, or QoL), more so than the exceptional paradigm of triage for combat medicine.^[8] The QALY accounts for “morbidity” and “social functioning” as well as predicted longevity, attributing “value” to particular lives and states of being—based largely on impairments, measured through QoL, ADL (activities of daily living), and similar scales. Taking a longer view, eugenic principles related to the quality and cost-effectiveness of certain lives continued to structure the emerging fields of medical accounting and management after World War II.^[9]

As disability activist, scholar, and bioethicist Joseph Stramondo argues, the decades-long attempts to come up with indices to *quantify* the quality of life in the name of making cost-saving decisions about medical technology and treatment create a “disability paradox”:

“There is a substantial gap between a disabled person’s self-assessment and how their quality of life is judged by folks that have never experienced their disability.”^[10]

Since the 1970s and ‘80s—when QALYs and QoL measures began to be employed on a broad scale—physicians, economists, policymakers, and nondisabled bioethicists have normalized these decision-making tools through repeated use, even though their format and reliability remain disputed.^[11] Thus, even as people with disabilities made unprecedented legal gains in the late twentieth century, ableism persisted in the medical and medical ethics fields. Although disabled people have won legal rights to equal medical care in the U.S., the gap between policy and practice is always negotiable and problematic.

This gap has only widened in the pandemic setting. The OCR is now investigating multiple complaints of disability rights violations. Despite recent federal assurances that discrimination is unacceptable in distributing medical resources, such proclamations don’t resolve the tough questions concerning disability-based triage during this pandemic. What happens, for instance, when someone using ASL enters a crisis-mode ER? What about someone who already uses a personal ventilator, and fears its requisition for a “better-scoring” patient? The OCR has responded to several lawsuits,^[12] and medico-legal struggles are ongoing. California disability activists won a ruling that personal ventilators cannot be reassigned upon hospital entrance. Along with many

disability activists and allies, we argue that these complex issues of medical care under Covid conditions of rationing must be examined with full input from disability perspectives. Indeed, a recent article in *The Hastings Center Report* made an important argument for recruiting disability bioethicists to all hospital-based ethics committees,

“The combination of physiology, ethics, and politics makes the disproportionate impact of COVID-19 on disabled people inescapable. As a matter of justice, we must more fairly distribute the benefits and burdens between individuals and groups and recognize the moral equality of individuals and groups. The representation of a diverse range of disabled people on triage committees would advance both of these goals.” [\[13\]](#)

Beyond protest and critique, disability activists have responded to the COVID-19 crisis with mutual aid and creative worldmaking, insisting on the lessons of longstanding disability grit and innovation, while helping us all to imagine a more equitable society to come when the pandemic recedes. Consider the words of Alice Wong, the indefatigable founder of the activist group Disability Visibility:

“It is a strange time to be alive as an Asian American disabled person who uses a ventilator. The coronavirus pandemic in the United States has disrupted and destabilized individual lives and institutions. For many disabled, sick, and immunocompromised people like myself, we have always [lived with uncertainty](#) and are skilled in adapting to hostile circumstances in a world that was never designed for us in the first place. Want to avoid touching door handles by hitting the automatic door opener with your elbow? You can thank the Americans with Disabilities Act and the disabled people who made it happen.”[\[14\]](#)

On webinars, Zoom conferences and parties, podcasts and social media posts, Wong and many other activists have drawn on their disability expertise and ingenuity to help us rethink who counts and who does the counting in this pandemic. The voices of people with disabilities and their allies have vividly described their frightening experiences, as well as innovative approaches for self-care, interdependence, and activism through opinion pieces in the mainstream press, online advocacy organizations, listservs, Facebook groups and consultations with relevant administrators at city hospitals. With titles like, “I will not apologize for my needs” and “My life is more ‘disposable’ during this pandemic”, these communiqués from the front make a powerful case for disability inclusion under these challenging conditions. Disability bioethicists and activists

have jumped in, insisting that this vanguard knowledge be included on all healthcare planning panels during pandemic recovery so that hard-won knowledge not once again be marginalized or lost.[\[15\]](#) As we have learned regarding the wide-ranging value of accessibility – from curb cuts to closed captions on tv – building a world that welcomes disabled people benefits everybody. Likewise, bioethics protocols need to be reframed with disability expertise not only in mind but at the table. Joe Stramondo reminds us of the life-saving significance of alternative models in medical decision-making that include a disability justice perspective.

“.....it’s important to talk not only about distributive justice and what’s fair when it comes to allocating resources...but also recognition justice. In other words, how we recognize different people and different groups of people as moral equals within a society...this isn’t just about picking the right people to maximize lives saved when using an allocation system for ventilators. It’s also about who we are as a society as we recognize the value of our different members and the equal moral value of each person”
[\[16\]](#).

Listening to creative disability leadership (rather than pronouncements formulated by medical authorities with scant disability expertise) enables everyone to learn how interdependency works in practice during a protracted crisis. In this, bioethics has a skilled tutor in the disability justice movement. As founders of NYU’s Center for Disability Studies, we are continually reminded of the high learning curve of the present, as we encounter again and again that disability is not only an ingenious way to live under conditions of discrimination,[\[17\]](#) but also maps a road forward toward a more just future in which every bodymind counts.[\[18\]](#)

[Faye Ginsburg](#) is David B. Kiser Professor of Anthropology at New York University where she founded and directs the Center for Media, Culture & History, and co-founded and co-directs The Center for Disability Studies. Author and editor of four books and many articles, she is completing a book with Rayna Rapp entitled Disability Worlds: Personhood, Everyday Life and “the New Normal” in the 21st Century.

[Mara Mills](#) is Associate Professor of [Media, Culture, and Communication](#) at New York University, where she co-founded and co-directs the [Center for Disability Studies](#). She is a founding editor of the journal Catalyst: Feminism, Theory, Technoscience. Most recently she co-edited Testing Hearing: The Making of Modern Aurality (forthcoming July 2020 from Oxford University Press) and, with Jonathan Sterne, is co-authoring a book titled Tuning Time: Histories of Sound and Speed. More information can be found at her website: maramills.org

[Rayna Rapp](#) is professor of anthropology at New York University, a co-founder of the Center for Disability Studies, and an affiliate of the College of Global Public Health. Her books and articles have focused on the politics of reproduction; gender and medicine, science studies, and disability and culture. Along with Faye Ginsburg she is completing a book entitled *Disability Worlds: Personhood, Everyday Life and “the New Normal”* in the 21st Century.

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Endnotes

- [1] Joel Michael Reynolds, 2018. “The Extended Body: On Aging, Disability, and Well-Being.” Hastings Center Report, Special Report, S32
- [2] “Ensuring Health Equity for People with Disabilities: The Context and Ethics of Health Rationing Protocols during COVID-19.” April 24 Webinar, The Radcliffe Institute.
- [3] Sunaura Taylor, “[What Would Health Security Look Like?](#)” *Boston Review*, 28 May 2020.
- [4] The Center for Public Integrity hosts an [interactive map with policies](#) by state, as of 8 April 2020.
- [5] “[Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019](#),” HHS Office for Civil Rights in Action, 28 March 2020.
- [6] “[Applying HHS’s Guidance for States and Health Care Providers on Avoiding Disability-Based Discrimination in Treatment Rationing](#),” The Bazelon Center for Mental Health Law, 3 April 2020 ; “[COVID-19 Medical Rationing](#),” The Center for Public Representation, accessed 1 June 2020; “[Fair Resource Allocation During the COVID-19 Pandemic](#),” The Ruderman Foundation, accessed 24 April 2020.
- [7] David S. Grimes, “Rationing Health Care,” *The Lancet*, 14 March 1987, 15-16. Grimes was not anti-QALY; he was also concerned about rationing being left in the hands of unprepared or overwhelmed doctors.
- [8] Milton Weinstein and William Stason, “Foundations of Cost-Effectiveness Analysis for Health and Medical Practices,” *The New England Journal of Medicine* 296, 13 (31 March 1977): 716-721.

[9] Eleanor MacKillop points to eugenics in the 1920s as a philosophical origin for QALYs and “cost of life.” See MacKillop, “[Valuing Life: Exploring the history of Quality-Adjusted Life-Years \(QALY\)](#),” *Remedia*, 3 May 2017. Other historians of health economics point farther back, to cost-benefit analyses of the loss of human lives by nationality during a 17th-century plague. See Evelyn L. Forget, “Contested Histories of an Applied Field: The Case of Health Economics,” *History of Political Economy* 36, 4 (Winter 2004): 617-637.

[10] Joseph Stramondo, “[COVID-19 Triage and Disability: What NOT to Do](#),” *Bioethics.net*, 30 March 2020.

[11] M. Pennachini, M. Bertolaso, M.M. Elvira, M.G. De Marinis, “A Brief History of Quality of Life,” *Clin Ter* 162, 3 (2011): e99-103.

[12] “[Disability Discrimination in the Rationing of Life Saving COVID Treatment: Who Gets Left Behind?](#)” American Bar Association, 14 April 2020; Michelle Diament, “[Feds Urged To Prevent COVID-19 Disability Discrimination](#),” Disability Scoop, 24 April 2020; “[OCR Resolves Civil Rights Complaint against Pennsylvania after it Revises its Pandemic Health Care Triage Policies to Protect Against Disability Discrimination](#),” U.S. Department of Health and Human Services, 16 April 2020.

[13] See also Savin, K. and L. Guidry-Grimes. “[Confronting Disability Discrimination During the Pandemic](#).” Hastings Bioethics Forum. 2 April 2020.

[14] Alice Wong, “[I’m Disabled and Need a Ventilator to Live. Am I Expendable During this Pandemic?](#)” Vox, 4 April 2020.

[15] Tsaplina, Marina, and Joseph A. Stramondo. “[#WeAreEssential: Why Disabled People Should Be Appointed to Hospital Triage Committees](#).” The Hastings Center, 15 May 2020. For an overview of the public health ethics stakes in disability justice, see also Savin, K. and L. Guidry-Grimes. “[Confronting Disability Discrimination During the Pandemic](#).” Hastings Bioethics Forum. 2 April 2020.

[16] Joseph Stramondo, “Ensuring Health Equity for People with Disabilities: The Context and Ethics of Health Rationing Protocols during COVID-19.” Webinar, The Radcliffe Institute, 24 April 2020.

[17] Devva Kasnitz, 2020. “The Politics of Disability Performativity: an Autoethnography,” *Current Anthropology* 61, no. S21 (February 2020): S16-S25. She, in turn, credits this observation to Neil Marcus, in Marcus, Neil, Devva Kasnitz, and Pamela Block. 2016. “If disability is a dance, who is the choreographer? a conversation about life occupations, art,

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