

PERSPECTIVE

COVID-19 Clinical Bias, Persons with Disabilities, and Human Rights

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Persons with disabilities have historically been discriminated against by society, including fulfilment of the right to equal access to health care.¹ The more egregious practices, historically as well as today, include outright denials of access to health care, involuntary sterilization, forced institutionalization, coerced treatment, and substituted decision-making.² Discrimination also occurs by more insidious practices. For instance, the public health construct of DALYS (disability adjusted life years) “neutrally” devalues the lives of persons with disabilities relative to the lives of those without disabilities.³ Along the same lines, commonly accepted norms and practices lessen the priority of persons with disabilities for essential procedures, such as organ transplants.⁴ Moreover, clinical bias disproportionately affects some disabled people, particularly those who occupy racialized, gendered, and sexually marginalized intersections.⁵ Finally, many otherwise laudable programs, such as United Nations HIV/AIDS programming, neglected for decades to include persons with disabilities.⁶ This essay considers types of clinical bias against patients with disabilities in the context of the COVID-19 pandemic, how such stigma impairs their equal access to health care, and how the application of international human rights norms would mitigate such impacts.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), the first international treaty to acknowledge the human rights of persons with disabilities, responds to this persistent social and programmatic exclusion.⁷ The CRPD is based on a deontological normative commitment to the ideal of the inherent value and worth of persons with disabilities—and all humans—as an end in itself and not a mere means to other ends.⁸ In addition to recognizing the inherent dignity, autonomy, and equal worth of persons with disabilities, the CRPD contains provisions explicitly relating to the equal provision of health care.⁹ Prominently, article 25 (health) recognizes that persons with disabilities “have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability,” and requires states parties to provide persons with disabilities “with the same range, quality and standard of free or affordable health care and programmes as provided to other persons.”¹⁰ Article 25 further mandates that states parties “provide those health services needed by persons with disabilities specifically because of their disabilities” and require health care personnel “to provide care of the same quality to persons with disabilities as to others.”¹¹ Relatedly, article 10 (right to life) reaffirms the equal quality of life of persons

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with disabilities by proclaiming that “every human being has the inherent right to life” such that states parties “shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.”¹² Connecting and enabling the rights contained in the CRPD are article 12 (equal recognition before the law) and interpretive General Comment 1, which assert that all persons possess the capacity to make decisions on an equal basis, regardless of disability, and underscore in the health care context that clinical determinations of patients lacking capacity cannot be grounds for circumventing the need for their consent to treatment.¹³ And wisely, article 8 (awareness-raising) requires “immediate, effective and appropriate measures” to “raise awareness,” “foster respect,” and “combat stereotypes, prejudices and harmful practices relating to persons with disabilities.”¹⁴

The CRPD has been ratified nearly universally, with the result that it has influenced health care laws and policies at both the domestic level (for example, some 32 states are currently revising their mental health laws) and globally (the Sustainable Development Goals, unlike their predecessor Millennium Development Goals, include persons with disabilities).¹⁵ These are great accomplishments, but stigma and lack of knowledge and awareness persist among health care providers both because of millennia-old instantiated social constructs and due to a lack of medical and public health education regarding persons with disabilities.¹⁶ We explicitly note that the United States—from which we draw several errant examples—remains within the minority of United Nations member states *not* to have ratified the CRPD, thus begging the question whether it lags behind global standards absent having this explicit rights framework in place to inform practice.

The COVID-19 pandemic, which is overwhelming health care systems and posing a dramatic threat to public health worldwide, highlights the issue of explicit and implicit bias against persons with disabilities in accessing health care and being treated equally and with full dignity therein. Reports from around the globe show how

biases that have always been present have become magnified by COVID-19. For instance, Romanians with disabilities with full-blown COVID-19 in institutional care have been quarantined instead of hospitalized, something that is not being done to those without disabilities.¹⁷ Descriptions of Guatemala’s sole public psychiatric hospital note that it is a “dumping ground” for persons with disabilities and a COVID-19 breeding ground.¹⁸ In the United States, there are claims of persistent discrimination against individuals with disabilities trying to access COVID-19-related health services, such as ventilators.¹⁹ Globally, the COVID-19 Disability Rights Monitor Dashboard—an organization that monitors experiences of injustice by persons with disabilities—has received approximately 1,600 complaints from people in more than 120 countries.²⁰

Moreover, clinical triage and treatment criteria predicated on social constructions rather than evidence-based studies have been promulgated and may result in standards that further discriminate against patients with disabilities when apportioning ICU beds, ventilators, and other care. At the start of the COVID-19 pandemic in the United States, for example, the state of Alabama explicitly recommended that patients with intellectual and developmental disabilities be viewed as ineligible for ventilators.²¹ Other US states issued similar triage and treatment guidance deprioritizing various categories of persons with disabilities; some of these crisis standards of care guidelines, after complaints to the US Office of Civil Rights, were subsequently amended to better ensure equal access and treatment.²² Nevertheless, some utilitarian-inclined academics have viewed these triage and treatment prioritizations, which give lower priority to persons with various disabilities, with approbation in some significant medical practitioner journals that are widely read and influence public policy.²³

In our view, much discussion regarding how to make the best decisions about which patients with COVID-19 should get care—and when and how—tends to presuppose that patients are philosophical abstractions with known prognoses and treatment costs that are fungible objects in a thought experiment. For instance, when discussing these kinds of

clinical decisions, it is common to hear questions framed thus: “Should you decline care to someone with features like patient X [often described as having a disability] so you can then offer care to three people with features like patient Y [usually, in these scenarios, described as being non-disabled]?”

Yet, contrary to abstractly grounded recommendations, real-life clinical decision-making is steeped in the richness of everyday clinical contexts and social textures and environmental impacts that often cannot be captured by top-down abstract formulations and recommendations. These details make all the difference in knowing the appropriate and ethical course of clinical care. Nonetheless, clinical decisions, especially in rapid and emergency situations—even when made in best faith—can be influenced by bias toward persons with various disabilities, such as patients with spinal cord injury, stroke, intellectual and developmental disabilities, and many other conditions.²⁴

To illustrate, let us consider COVID-19 care for a patient with paraplegia who has lost motor function and control below the waist. Even if we believe that all people with the same diagnosis or level of COVID-19 pathophysiology should have equal access to care, there are certain biases that distort how we estimate likelihoods of treatment success and survival. Specifically, as explained below, when viewing patients such as this patient with paraplegia, and when facing the same medical facts, we are likely to be more pessimistic about prognosis, treatment success, and survival and more likely to underestimate patient resilience. This is due to a number of biases that exist among the general public that also manifest in clinical life. These biases have been described at length, and we contextualize them here.²⁵ We address four biases in particular: ineffectual bias, fragility bias, friendliness bias, and catastrophe bias.

With “ineffectual bias,” there is a systematic assumption that patients with disabilities are lower in agency and competence than non-disabled patients with the same presenting medical complaint. This leads to patients with disabilities being treated with more paternalism by their clinicians. For instance, a patient with paraplegia’s subjective experiences

and choices are more likely to be discounted, when in fact respect for article 12 of the CRPD would imply that the patient should be the lead decision maker.²⁶ Amidst COVID-19, this would manifest as clinicians being more likely to act on behalf of a patient with paraplegia and not taking into account the patient’s autonomous preferences concerning care, whether in declining desired treatment or advocating for treatment when undesired.

With “fragility bias,” patients with disabilities are perceived as suffering more and having more severe symptoms than non-disabled patients with the same presenting medical facts. Amidst COVID-19, this would lead to less intensive and more conservative treatments that clinicians believe patients with disabilities “can handle.” These patients’ resilience and endurance would be underestimated, and care would be withdrawn earlier. This would undermine the obligations inherent in article 25 of the CRPD, as equal treatment and equal access to the same standard of health means that patients with paraplegia should get the same treatment and chance at attaining the highest standard of health as everyone else within their operative health care systems.

With “friendliness bias,” patients with disabilities are attributed as possessing greater warmth, trustworthiness, and prosociality than patients without disabilities. In the context of COVID-19, this clinical saintliness bias would manifest in a greater presumption by clinicians that patients with disabilities would be willing to give up their lives to save others amidst scarce resources. This tendency would be in conflict with article 10 of the CRPD, which suggests that respect for persons with disability as having equal dignity means that one cannot presuppose just by virtue of their disability that they necessarily have a lower quality of life or self-regard themselves less due to disability and can therefore be deprioritized for limited health care resources. The patient with paraplegia—just like any non-disabled person—should therefore be presumed to be both worthy of and wanting to be cured and live despite COVID-19, unless evidence suggests otherwise.

With “catastrophe bias,” the clinician will tend

to project more catastrophe onto the patient with a disability than the patient actually experiences. With this bias, COVID-19 patients with disabilities, such as the patient with paraplegia we are discussing, would be perceived as having less quality of life and more mourning concerning their situation than if they were not disabled. This leads to more clinical pessimism, as well as a higher threshold for initiating treatment and a lower threshold for withdrawing it. Clinicians are likely to “give up” sooner than they would for non-disabled patients. There is less hope for a good prognosis and a resilient patient who can endure the struggle of hospitalization. The entirety of the CRPD, and especially article 10, gives us normative weight against this bias, as the equal value and inherent worth of all patients with disabilities means that we cannot presuppose more catastrophe for the patient with paraplegia than is warranted by the standards of clinical history taking and evidence that would apply to any patient regardless of disability status.

We offer this information to help clinicians step back to engage in critical reflection about the processes that enter their minds when making treatment decisions for their COVID-19 patients with disabilities, and to help clinicians, scholars, policy makers, patients, family members, and advocates ensure that none of the above biases are distorting perceptions of patient prognosis, how likely treatment is to be successful, how likely patients are to benefit from treatment, how likely patients are to survive after treatment, and how resilient patients may be throughout the treatment and recovery process. This information is especially relevant in high-stakes emergency and critical-care settings, where clinical decisions about intensity and goals of care are soaked in value judgments that are particularly prone to contamination by the kinds of biases we have described that affect persons with disabilities.

Hope is crucial for the therapeutic alliance and treatment success. Patients with disabilities have enough barriers to adequate care, ranging from lack of physical and sign-language accessibility and inadequate insurance coverage to “inadvertent” discrimination (for example, CT machines

that little people cannot reach) to outright stigma (declining *in vitro* fertilization to women with disabilities because they would be “inappropriate” parents). Clinical life is ever more precarious if the biases of clinicians dissolve some of the hope that would otherwise be present between patient and clinician. While it is true that clinicians need to know more about their legal obligations to persons with disabilities related to required accommodations, everyday moral decisions are also important and probably more immediate, especially during pandemics such as COVID-19.

A lesson that ought to be reinforced from the experiences of the COVID-19 pandemic is that, at its most humane, clinical medicine is and should be situated in life as it is lived, for better or worse. Patients should be acted on as non-interchangeable precious particulars with unique needs, not generic abstractions or aggregates with equal baseline social situations. Another lesson is one that patients with disabilities have always known: even with the same diagnosis and treatment plan, life is more precarious not because of inequality in pathophysiology but due to inequity in cultural, historical, and social psychological factors, as well as normative anti-human rights presuppositions that creep into philosophical formulations of what constitutes “ethical” health care. Disparities arise from how we see one another and the degree to which we see dignity in one another as fully and equally human and as bearers of human rights. Finally, a lesson that has been dramatically highlighted by the COVID-19 pandemic is that clinicians can be disability rights agents for change.²⁷ Clinicians committed to human rights should resist the scrupulous ethical myopia of utilitarian thinking in the clinic and should empower their patients with disabilities and their colleagues to see clinical life and the health care needs of those with disabilities not with a lens of bias and burdensomeness, but with a lens of dignity, equality, and disability-based human rights.

References

1. L. P. Francis, A. Silvers, and M. A. Stein, “Disability and health law,” in I. G. Cohen, A. K. Hoffman, and W. M.

- Sage (eds), *The Oxford handbook of U.S. healthcare law* (New York: Oxford University Press, 2016), pp. 1–29.
2. M. A. Stein, P. J. S. Stein, and P. Blanck, “Disability,” in S. N. Katz (ed), *The Oxford international encyclopedia of legal history* (New York: Oxford University Press, 2009).
 3. J. Fox-Rushby, “Disability-adjusted life years (DALYs) for decision-making?: An overview of the literature,” Office of Health Economics. Available at <https://www.ohe.org/publications/disability-adjusted-life-years-dalys-decision-making>.
 4. E. A. Largent, “Disabled bodies and good organs,” in I. G. Cohen, C. Shachar, A. Silvers, and M. A. Stein (eds), *Disability, health, law, and bioethics* (Cambridge: Cambridge University Press, 2020), pp. 104–116.
 5. S. Yee, M. L. Breslin, T. D. Goode, et al., *Compounded disparities: Health equity at the intersection of disability, race, and ethnicity* (roundtable workshop on the intersection among health disparities, health equity, and health literacy, Washington, DC, 2017).
 6. M. A. Stein, C. McClain-Nhlapo, and J. E. Lord, “Education and HIV/AIDS: Disability rights and inclusive development,” in M. Langford, A. Sumner, and A. E. Yamin (eds), *The Millennium Development Goals and human rights: Past, present and future* (New York: Cambridge University Press, 2013), pp. 274–294.
 7. Convention on the Rights of Persons with Disabilities, G.A. Res. A/61/106 (2007); I. Bantekas, M. A. Stein, and Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A commentary* (Oxford: Oxford University Press, 2019).
 8. Convention on the Rights of Persons with Disabilities, G.A. Res. A/61/106 (2007); Bantekas et al. (see note 7).
 9. M. A. Stein, “Disability human rights,” *California Law Review* 95/1 (2007), pp. 75–121; M. A. Stein, P. J. S. Stein, R. Lang, et al., “Health care and the UN Disability Rights Convention,” *Lancet* 374/9708 (2009), pp. 1796–1798.
 10. Convention on the Rights of Persons with Disabilities, G.A. Res. A/61/106 (2007), art. 25(a).
 11. *Ibid.*, art. 25(b), (d).
 12. *Ibid.*, art. 10.
 13. *Ibid.*, art. 12.; Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014): Article 12; Equal Recognition before the Law, UN Doc. CRPD/C/GC/1 (2014); M. A. Stein, F. Mahomed, V. Patel, et al. (eds), *Mental health, legal capacity, and human rights* (Cambridge: Cambridge University Press, forthcoming).
 14. Convention on the Rights of Persons with Disabilities, G.A. Res. A/61/106 (2007), art 8.
 15. United Nations Department of Economic and Social Affairs, *Convention on the Rights of Persons with Disabilities (CRPD)*. Available at <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>; UN General Assembly, Report of the Special Rapporteur on the Rights of Persons with Disabilities to the Human Rights Council, UN Doc. A/HRC/37/56 (2017); UN Department of Economic and Social Affairs, *Sustainable development [homepage]*. Available at <https://sdgs.un.org>.
 16. L. M. Meeks and N. R. Jain, *Accessibility, inclusion, and action in medical education: Lived experiences of learners and physicians with disabilities* (Washington, DC: Association of American Medical Colleges, 2018); M. A. Stein, J. E. Lord, and D. W. Tolchin, “Equal access to health care under the UN Disability Rights Convention,” in R. Rhodes, M. Battin, and A. Silvers (eds), *Medicine and social justice: Essays on the distribution of care* (New York: Oxford University Press, 2012), pp. 245–254.
 17. European Network on Independent Living, *Urgent appeal requesting access to COVID-19 medical treatment in Romania* (June 2020). Available at <https://enil.eu/news/urgent-appeal-requesting-access-to-medical-care-in-romania>.
 18. N. Larsson, “Officials conceal conditions at Guatemala mental health hospital during pandemic,” North American Congress on Latin America (June 23, 2020). Available at <https://nacla.org/news/2020/06/23/guatemala-mental-health-hospital-covid>.
 19. E. Pendo, “Covid-19 and disability-based discrimination in health care,” American Bar Association (May 22, 2020). Available at <https://www.americanbar.org/groups/diversity/disabilityrights/resources/covid19-disability-discrimination>.
 20. European Network on Independent Living, the Validity Foundation, the International Disability Alliance, et al., *COVID-19 disability rights monitor* (2020). Available at <https://covid-drm.org>.
 21. S. Fink, “U.S. civil rights office rejects rationing medical care based on disability, age,” *New York Times* (March 28, 2020). Available at <https://www.nytimes.com/2020/03/28/us/coronavirus-disabilities-rationing-ventilators-triage.html>.
 22. A. Ne’eman, “When it comes to rationing, disability rights law prohibits more than prejudice,” *Hastings Bioethics Forum – The Hastings Center* (April 10, 2020). Available at <https://www.thehastingscenter.org/when-it-comes-to-rationing-disability-rights-law-prohibits-more-than-prejudice>.
 23. E. J. Emanuel, G. Persad, R. Upshur, et al., “Fair allocation of scarce medical resources in the time of Covid-19,” *New England Journal of Medicine* 382 (May 21, 2020), pp. 2049–2055.
 24. M. A. Budd, O. S. Haque, and M. A. Stein, “Biases in the evaluation of self-harm in patients with disability due to spinal cord injury,” *Nature: Spinal Cord Series and Cases* 6 (May 27, 2020); M. J. Young, R. W. Regenhardt, T. M. Leslie-Mazwi, and M. A. Stein, “Disabling stroke in persons already with a disability: Ethical dimensions and directives,” *Neurology* 94/7 (February 18, 2020), pp. 306–310; D. S. Dunn, *The social psychology of disability* (New York: Oxford University Press, 2014); G. L. Krahn and M. H. Fox, “Health disparities of adults with intellectual disabilities: What do

we know? What do we do?" *Journal of Applied Research in Intellectual Disabilities* 27/5 (September 2014), pp. 431-446.

25. Dunn (see note 24); O. S. Haque and M. A. Stein, "Humanizing clinical care for patients with disabilities," in I. G. Cohen, C. Shachar, A. Silvers, and M. A. Stein (eds), *Disability, health, law, and bioethics* (Cambridge: Cambridge University Press, 2020), pp. 117-128.

26. Budd et al. (see note 24); Dunn (see note 24); Haque and Stein (see note 25).

27. M. Bristo, C. A. Blauwet, W. Frontera, et al., "The Convention on the Rights of Persons with Disabilities: What is at stake for psychiatrists and the patients we serve," *Journal of Physical Medicine and Rehabilitation* 6/4 (2014), pp. 356-362.