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Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care

by LAURA GUIDRY-GRIMES, KATIE SAVIN, JOSEPH A. STRAMONDO, JOEL MICHAEL REYNOLDS, MARINA TSAPLINA, TERESA BLANKMEYER BURKE, ANGELA BALLANTYNE, EVA FEDER KITTAY, DEVAN STAHL, JACKIE LEACH SCULLY, ROSEMARIE GARLAND-THOMSON, ANITA TARZIAN, DORON DORFMAN, and JOSEPH J. FINS

The Covid-19 pandemic has highlighted systemic disadvantages that people with disabilities face in the health care system. While catastrophic health emergencies demand an immediate response that often precludes addressing underlying systemic discrimination, there is a moral duty to shine a light on structural disability bias that may distort how crisis standards of care are put into practice. We suggest practical ways, now or in the future, to shift the construction, implementation, and institutional context of crisis standards of care toward disability justice,¹ anchoring our discussion in the 2010 Institute of Medicine’s “Summary of Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations.” We elaborate on the four elements of the IOM vision statement: fairness; equitable processes; community and provider engagement, education, and communication; and the rule of law.²

Interpreting these elements through disability justice entails a commitment to both recognitive and distributive justice. Daniel Putnam et al.’s “Disability and Justice” summarizes Nancy Fraser’s distinction: “Recognition seeks to secure equal respect for individuals to whom it has been denied; redistribution seeks to correct unfair

disparities in advantages of various kinds.”³ The concept of recognitive justice underwrites the disability rights movement’s demand “Nothing about us without us,” which requires substantive inclusion of disabled people in decision-making related to their interests.⁴ The participatory parity advocated by both this slogan and Fraser’s work entails acting in good faith to accommodate differences based on self-identified interests that can be adequately appreciated only through the meaningful participation of disabled people in the construction and implementation of crisis standards of care. Of course, recognitive and distributive justice interlock in ways that make them inseparable, especially given how ableism, ageism, racism, and other forms of oppression and marginalization are jointly constructed.

We argue for the full recognition of the moral equality of disabled people in formulating crisis standards of care and in modifying social and institutional practices in light of the inequities that the crisis highlights and exacerbates, such that the demand “Nothing about us without us” is truly met. Below, we offer concrete recommendations for reforms before, during, and after a public health emergency.

Fairness

According to the IOM, fairness requires that crisis standards of care “are, to the highest degree possible, recognized as fair by all those affected by them” and responsive to evidence as well as to the “specific needs of individuals and the population.”⁵ This includes du-

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The pandemic has brought attention to the value of disabled knowledge as society makes collective accommodations for our newly remote lives. We call for formal inclusion of disability perspectives in institutional and governmental decision-making bodies.

ties of compassion and care, responsible stewardship, and maintaining trust.

People who rely on long-term care can be especially vulnerable in a public health crisis, and fairly constructed and implemented crisis standards of care must account for this vulnerability. For example, the Covid-19 pandemic has had a devastating impact on congregate care settings like nursing homes, state institutions, psychiatric hospitals, and group homes.⁶ Proactive crisis planning should ensure that these residences have the staff members and resources they need to cope with a pandemic. The Centers for Disease Control and Prevention's suggested restrictions on visitors and communal dining⁷ are particularly onerous for residents in these settings. Many cannot practice physical distancing, self-monitor their symptoms, or communicate their needs independently. They rely on staff members to ensure their safety and well-being. Many of the same features of congregate care settings that make their residents vulnerable to Covid-19 have been identified by disability activists and scholars as discriminatory and oppressive since long before this pandemic.⁸ Significant investment in congregate care settings is required to rethink their architectural design (such as the need for separate toilet facilities to reduce contagion), improve remote forms of communication and recreation, carry out advance planning in case of public health disasters, obtain resources that will diminish the hazards of catastrophic events, and establish protocols for ombudspersons to safely monitor facilities, even under pandemic restrictions.

Additionally, some people who rely on home- and community-based care services (HCBS) and self-direct this care with personal care attendants have experienced service disruptions during the Covid-19 pandemic because these care providers were not clearly designated and protected as essential workers at the federal level. Crisis standards of care should recognize the critical nature of "outpatient resources" such as HCBS. If crisis plans do not adequately take into account the heightened risk to workers in HCBS during a pandemic, they will place undue burden on these caregivers and also endanger the lives and well-being of disabled people who rely on this care. Therefore, these caregivers should be classified as essential, have additional work protections (paid sick leave should be instituted before a public health crisis hits), and be prioritized in the distribution of personal protective equipment. Moreover, chronic-use ventilators in

homes and facilities should be explicitly protected from allocation schemas; as one of us (Joseph Fins) has emphasized, citing guidelines from the New York State Task Force on Life and the Law, reallocating personal ventilators "fails to follow the ethical principle of duty to care and could be construed as taking advantage of a very vulnerable population."⁹

Compassion, care, and trust are also major issues in hospital settings. For example, some people with disabilities require continual bedside caregiving in the hospital that an overwhelmed hospital staff may not be able to provide even in an intensive care unit. This extra caregiving would typically be supplied by family members or attendants who have long-standing relationships with the patients and knowledge of their needs. In ordinary times, such caregivers can be uniquely positioned to enable communication and shared decision-making with these patients, which can be especially important for disabled women or people of color, who are less likely to be believed when they report pain and other symptoms.¹⁰ During a public health crisis, such advocacy may be precluded by stringent visitation policies. To the extent reasonable in a crisis, hospital visitation should be permitted for patients with communication or intellectual disabilities. If a hospital cannot accommodate visitation, then white boards, prominent medical record documentation, and telemedical equipment should be used to ensure the patient's needs are well-known to the staff. These methods can also help clarify the patient's baseline status and preferred modes of communication.

Numerous recommendations have been made about fair stewardship of scarce resources.¹¹ Triage considerations should be based in individualized assessments of patients' medical situations. Categorical exclusions based on diagnosis immediately lose the nuanced, contextualized picture that should inform medical teams' evaluations of appropriate medical care. Any scoring system for setting triage priorities, like the Sequential Organ Failure Assessment, should be carefully reviewed to ensure that it does not assign points based on inappropriate considerations, such as categorical assumptions about disability type. Even if the design of SOFA scoring is not meant to be discriminatory on the basis of disability,¹² it could nonetheless be implemented to have that effect. The use of SOFA must therefore be reviewed to ensure adequately individualized application of the scores—for example, accommodating nonverbal patients or patients

with neuromuscular disabilities who cannot easily respond to commands.¹³ If disabled persons are part of the planning processes surrounding the development of crisis standards of care, then it is more likely that implementation of scoring systems can avoid errors and misapplications; triage teams can receive the appropriate training up front about how to review and correct triage scores that have mistakenly deprioritized patients with disabilities. The processes used to formulate crisis standards of care should minimize bias; the importance of this is made clear by the long and fraught history of ableism in medicine.¹⁴

Equitable Processes

As the IOM recommends, crisis standards of care must be transparent, consistent, proportional, and accountable to those affected by them.¹⁵ In developing and implementing crisis standards of care, health care systems should incorporate the perspectives of the disability community,¹⁶ many members of which are susceptible to heightened access barriers and severe illness in a pandemic.

The design and justification of crisis plans should always be transparent to the public, since it is the public who will bear the consequences of those plans. Transparency benefits the public by promoting public trust in medical systems, and these gains are particularly important for disability communities. A long history of medical abuse contributes to distrust in medical systems, and avoidance of health care due to fears of discrimination can become more acute during a pandemic.

In the event that a scarce resource allocation plan is implemented, having a triage committee, as opposed to a single triage officer, for a hospital or other institution may provide a better safeguard against the effects of personal bias, as committee members may be able to hold each other accountable for possible bias. Such committees should make individualized assessments but should not receive any information about patients that could be biasing or stigmatizing, such as name, socioeconomic status, ethnicity, or any disability that is medically irrelevant for the particular decision being made.¹⁷ Although this recommendation is not new, few protocols explicitly state this limit to patient information.¹⁸ A mechanism should be set up to oversee the work of these committees, to ensure equity, consistency, and the minimization of bias in their procedures and decisions. Depending on the institution and its capacity during a crisis, an independent oversight board could serve this function. Everyone who serves on a triage committee or oversight board should receive training in preventing disability discrimination.

Equitable processes are easier to achieve if the real effects of the Covid-19 pandemic on persons with disabilities are better understood. Public health agencies and health care institutions should invest in data collection on Covid-19 testing, diagnoses, the care received, and deaths by disability status. These results should be analyzed and published

openly to strengthen health care systems and improve preparations for future public health crises.¹⁹

Community and Provider Engagement, Education, and Communication

The IOM states that the development of crisis standards of care should involve “active collaboration with the public and stakeholders.”²⁰ The Covid-19 pandemic has already brought attention to the value of disabled knowledge as society makes collective accommodations for our newly remote lives, and we call for formal inclusion of disability perspectives in institutional and governmental decision-making bodies. These inclusive bodies should be as free from external political pressures as possible to preserve the actual perspectives and recommendations of the disability community. Efforts toward inclusion should also reflect the intersectional lives that disabled people live. Simply asking for representation from local mainstream disability advocacy organizations and coalitions is not enough because mainstream disability organizations may replicate the structures of injustice that are embedded in society, such as racism.²¹

The Covid-19 response has been marked by rapid change and quick communications, which often impede access unless communication accessibility has been mindfully factored into crisis standards of care planning. Examples of this problem include inaccessible communication across a variety of platforms during the pandemic, as seen in uncaptioned press conferences and in medical facilities where access to communications devices has been limited.²² Planning for communication in multiple modes and different registers (from Simple English to audio description to captioning to signing) is critical to provide disabled people with access to information. Without intentional communication access, public health systems directly jeopardize the safety and well-being of disabled people. Having well-established relationships with members of disability communities is one way to recognize and reduce these injustices. Engagement with the local disability community will help health care institutions respond to the real and evolving needs of this population.

Proactive outreach will help decrease the service burden on disabled people in the midst of a crisis, and insights gained from these interactions should inform planning before a crisis. Once the Covid-19 pandemic moves past the crisis stage, all health care systems should hold accessible community fora to rebuild trust, to learn, and to grow in how they care for disabled people in a pandemic.

The Rule of Law

The rule of law, as put by the IOM, requires the authority “to empower necessary and appropriate actions and interventions” in a public health crisis as well as the environment to facilitate the implementation of crisis standards of care.²³ On March 24, 2020, U.S. Secretary of Health and Human Services Alex Azar sent a letter to all state governors

calling on them to provide guidance designed to “alleviate medical malpractice liability for in-state healthcare professionals” working during the pandemic.²⁴ This step reassures health care providers that if they deviate from the standard of care due to resource or staff shortages during a catastrophic health emergency, they will be protected from civil or criminal liability. Our worry is that, without any threat of liability, health care providers will deprioritize accommodating people with disabilities without adequate justification. For this reason, proactive training for crisis standards of care is important. The Glasgow Coma Scale (which is one component of the SOFA score used in many triage protocols) provides an example of our concern. The “best verbal response” component of this scale yields a poorer score for patients who articulate “incomprehensible words” or “inappropriate sounds.” By providing augmented or alternative forms of communication to patients who have a speech disorder or who are deaf or hearing impaired, clinicians should gain a better grasp of the need to adjust the Glasgow Coma Scale verbal response score. (While crisis standards of care require adapting to unforeseen conditions in creative and atypical ways, accommodation here may be as simple as ensuring that patients have access to adequate free Wi-Fi to download and use language interpretation apps.) This example of how implicit bias may disadvantage persons with disabilities is not hypothetical; such bias has been shown to affect clinicians’ judgments about a patient’s health, lifespan, or quality of life.²⁵

Antidiscrimination mandates exist for a purpose, and they may not be completely waived during health emergencies—in fact, they are even more important at such times, when individuals who are marginalized by society experience heightened vulnerability. Immunity provisions enacted by states should therefore have specific exceptions related to statutory antidiscrimination that protect people with disabilities. Although uncertainties regarding Covid-19 abound, past public emergencies, such as hurricanes Katrina and Rita, demonstrated how emergencies can exacerbate existing inequities. A difficult balance needs to be found between allowing providers the freedom and confidence to do their jobs and recognizing the biases and misperceptions surrounding disability.

Further Challenges

Covid-19 reminds us that crisis periods can swiftly magnify existing health inequities. In acknowledgment that disability communities face systemic barriers to equitable care at baseline, the need for expediency posed by a pandemic must be balanced with intentional and preventative antidiscrimination efforts, in consideration of both distributive and cognitive justice. We have mostly focused on people who have long-term-care needs and accessible-communication needs, but there are additional chronic illness and disability needs, such as better management of treatment disruptions by hospitals, that also deserve attention.

The work of disability rights groups during this crisis should help advance the field of bioethics so it continues to develop as a disability-conscious field of inquiry and practice.²⁶

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16. Disabled people should also have paid leadership roles in public health. The U.S. Federal Emergency Management Agency, for example, hired Linda Mastandrea as the director of the Office of Disability Integration and Coordination, whose website reads, “The office leads FEMA’s commitment to whole-community emergency management by integrating individuals with disabilities and others with access and functional needs into all aspects of disaster preparedness, response, recovery and mitigation” (<https://www.fema.gov/linda-mastandrea>).

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