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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, Maria 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. *Hastings Center Report*, 2020¹*

Short summary: In this article Guidry-Grimes et al. argue for a shift in focus in crisis standards of care toward disability justice. With reference to the inequities encountered and exacerbated by the pandemic, the authors argue for full moral recognition of disabled people in development and modification of crisis standards of care. Practical suggestions are provided on basis of an elaboration of the four vision statements of the 2010 Institute of Medicine’s “Summary of Guidance for Establishing Crisis Standards of Care.”

Introduction

The 2010 Institute of Medicine’s “Summary of Guidance for Establishing Crisis of Standards of Care” - referred to as the IOM - outlines four elements in its vision statement: Fairness, equitable processes; community and provider engagement, education, and communication; and the rule of law. The authors interpret these elements from a disability justice perspective and argue for “substantive inclusion of disabled people in decision-making related to their interests.” (p. 28).

Key arguments:

- **Fairness:** Public health measures such as physical distancing are a challenge for disabled people living in congregate care settings, who are often heavily dependent on staff members to ensure their safety and well-being. Long term planning to increase safety for disabled people in public health crises should include investment in and design of congregate settings to reduce the risk of disease spreading in these facilities. The pandemic has also highlighted the vulnerability of people who are supported by home and community-based services to service disruptions and the need to take into account the risk to support workers in home and community settings. Other concerns about fairness raised by the authors relate to the application of Sequential Organ Failure Assessment scoring in triaging and reallocation of ventilators. Guidry-Grimes et al. argue that disabled persons should be directly engaged in developing crisis standards to minimize biases that may otherwise contribute to de-prioritization of disabled persons in the triaging process.

¹ Guidry-Grimes, L, K. Savin, J.A. Stramondo, J.M. Reynolds, M. Tsaplina, T. Blankmeyer Burke, A. Ballantyne, E.F. Kittay, D. Stahl, J. Leach Scully, R. Garland-Thomson, A. Tarzian, D. Dorfman, and J. J. Fins. *Hastings Center Report* 50(3): 28-32.

- **Equitable processes:** Crisis standards of care should incorporate the perspectives of disabled persons. An equitable process is best achieved if those who are impacted by the crisis standards of care are involved in the development and implementation of such standards. Suggested measures to mitigate the impact of personal biases in triage processes in hospitals and other institutions, include establishing a triage committee rather than a triage person. Moreover, triaging should involve assessment of every individual case, but without receiving any non-medically relevant information about patients that could invoke bias or stigma.
- **Community and provider engagement, education, and communication:** According to the IOM, crisis standards of care should be developed with direct involvement of the public and stakeholders. Guidry-Grimes et al. call for “formal inclusion of disability perspectives in institutional and governmental decision-making bodies.” (p.30). Attention must be paid to accessibility of communication to ensure the safety and well-being of people with disabilities. This includes ensuring appropriate access to communication devices in medical facilities and captioning of public health press conferences, for example. Direct involvement of the disability community is important to respond to emerging communication needs.
- **The rule of law:** According to the IOM, the rule of law involves the authority “to empower necessary and appropriate actions and interventions.” (p. 30). The authors argue that the need to allow health care providers the freedom to do their job during a time of crisis must be carefully balanced with the antidiscrimination mandate. With reference to the U.S Secretary of Health and Human Services’ letter of March 24, 2020, which called for deviation from standard of care during crisis, the authors highlight the risk of health care providers deprioritizing accommodation of disabled people. The authors also highlight implicit biases in the Glasgow Coma Scale, to illustrate how such biases contribute to disadvantaging disabled people.

Conclusion

The COVID-19 pandemic has highlighted vulnerabilities and systemic barriers to equitable care of disabled people during crises. The urgent need to address the pandemic threat should be carefully balanced with the need for intentional and preventative antidiscrimination efforts.