

Disability, Ethics, and Health Care in the COVID-19 Pandemic

This article considers key ethical, legal, and medical dilemmas arising for people with disabilities in the COVID-19 pandemic. We highlight the limited application of existing frameworks of emergency planning with and for people with disabilities in the COVID-19 pandemic, explore key concerns and issues affecting the health care of people with disabilities (i.e., access to information and clinician–patient communication, nondiscrimination and reasonable accommodations, and rationing of medical goods), and indicate possible solutions. Finally, we suggest clinical and public health policy measures to ensure that people with disabilities are included in the planning of future pandemic-related efforts.

The devastation evoked by the COVID-19 pandemic raises challenging dilemmas in bioethics. It also speaks to social justice issues that have plagued historically marginalized communities in the United States.

Responses to the pandemic must be bound by legal standards, principles of distributive justice, and societal norms of protecting vulnerable populations—core commitments of public health—to ensure that inequities are not exacerbated, and should provide a pathway for improvements to ensure equitable access and treatment in the future. (*Am J Public Health*. Published online ahead of print August 20, 2020: e1–e5. doi: 10.2105/AJPH.2020.305837)

Maya Sabatello, LLB, PhD, Teresa Blankmeyer Burke, PhD, Katherine E. McDonald, PhD, and Paul S. Appelbaum, MD

The COVID-19 pandemic has stretched the capacities of health care systems and raised challenging ethical dilemmas. With the unprecedented, rapid spread of infection, COVID-19 testing and care capacities have been overwhelmed. As health care professionals, families, and society grapple in real time with life-or-death decisions regarding equitable access to testing, shortages in personal protective equipment, rationing of medical goods, and clinicians' distress, the need for comprehensive emergency plans and guidelines is more critical than ever. Yet, as the pandemic wreaks havoc globally, its wide-ranging impacts on people with disabilities have received relatively little attention. Many people with disabilities—a large and diverse group encompassing individuals with a range of functional impairments, from mobility limitations to blindness or low vision and intellectual disability—are not necessarily at higher risk for contracting COVID-19. However, some subgroups are, and, more generally, the absence of strong national policies to accommodate the needs of this population significantly disadvantages the ability of many people with disabilities to protect themselves from COVID-19. This neglect may result in many people with disabilities being left behind.

People with disabilities have only recently begun to be

recognized by the field of public health as a population with significant health disparities. Notwithstanding its large size—20% of children and 26% of adults in the United States, by estimates of the Centers for Disease Control and Prevention (CDC)^{1,2}—this community remains highly marginalized and is underserved and underresearched. Compared with the general public, people with disabilities have less education; more economic, food, housing, and employment insecurity; and less Internet access.³ Although the rate of chronic medical conditions (e.g., obesity and cardiovascular disease) may be higher among some subgroups (e.g., people with mobility and intellectual disability),³ the CDC reports that, overall, “adults with disabilities are three times more likely than adults without disabilities to have heart disease, stroke, diabetes or cancer.”⁴ In addition, studies show that the prevalence of disability, including unmanaged chronic medical conditions, is disproportionately high among racial/ethnic minorities, including American Indian/Alaska Native communities.⁵

This puts people with disabilities in double jeopardy for marginalization in routine and preventive health care^{5,6} and, as demonstrated with COVID-19, in emergency preparedness and care.

There are only limited data on emergency planning for people with disabilities, but the need for tailored approaches to support this population during emergencies is not new. In the United States, such efforts have been catalyzed by media coverage of 9/11 and Hurricane Katrina, highlighting the failure to evacuate people with disabilities during times of disaster.⁷ More recently, during the H1N1 pandemic, the CDC called for recognition of people with mobility and cognitive disabilities as a high-risk group for developing influenza-related complications.⁸

Yet, existing emergency guidelines have limited application to the COVID-19 pandemic. For instance, the recommendation by the CDC and the Federal Emergency Management Agency (FEMA) that people with disabilities respond to disasters such as the H1N1 pandemic by utilizing a

ABOUT THE AUTHORS

Maya Sabatello and Paul S. Appelbaum are with the Center for Law, Ethics, and Psychiatry, Department of Psychiatry, Columbia University, New York, NY. Teresa Blankmeyer Burke is with the Department of History, Philosophy, Religion, and Sociology, Gallaudet University, Washington, DC. Katherine E. McDonald is with the Department of Public Health, Falk College, Syracuse University, Syracuse, NY.

Correspondence should be sent to Maya Sabatello, NY State Psychiatric Institute, 1051 Riverside Dr, Unit 122, New York, NY 10032 (e-mail: ms4075@columbia.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

This article was accepted June 11, 2020.

doi: 10.2105/AJPH.2020.305837

“personal support network” comprising several people^{8,9} has limited relevance to COVID-19. With stay-at-home and social distancing orders invoked because of the pandemic, the access of some people with disabilities to personal care assistants who provide direct support in their daily lives has been restricted.¹⁰ Although FEMA has in recent years highlighted the responsibilities of local governments to include people with disabilities in the planning, integration, and implementation of emergency programs,¹¹ consolidated and consistent guidelines are lacking.¹² As states, hospitals, health care systems, and residential settings for people with disabilities move to develop responses to the pandemic, it is critical to explore key issues likely to have an impact on their care. We consider 3 key issues: access to communication and medical information, nondiscrimination and reasonable accommodations, and rationing of medical goods.

COMMUNICATION AND MEDICAL INFORMATION

Although the scientific understanding of COVID-19 is limited, communicating the risks, measures of prevention, and treatment options before, during, and after the emergency are key to slowing down a pandemic and improving health outcomes. However, there are reasons to believe that people with some disabilities have been underinformed about COVID-19 and its ramifications. Consider the following: information conveyed via charts and graphs is inaccessible for blind and low-vision individuals and incomprehensible for people with intellectual

disability (and others) if not provided in plain language. Similarly, news briefings conducted without captioning or qualified American Sign Language interpreters preclude deaf and hard-of-hearing individuals from being informed.

As underfunded organizations of and for people with disabilities are forced to replace governmental functions and scramble to develop accessible information, additional challenges have emerged. The reliance on drive-through COVID-19 testing facilities when public transportation is restricted makes it difficult for blind and low-vision individuals and people with developmental disabilities to be tested and seek care. The transition to telehealth is appropriate in a pandemic but raises other challenges. For instance, automatic answering systems with multiple options are difficult, even impossible to use for many people with intellectual disability, deaf and hard-of-hearing individuals, or those with physical or speech-related disabilities that impede navigating these communication systems. Telehealth options may also be challenging for people with psychiatric conditions who, because of stigma, may conceal their condition and treatment from family members¹³ or who cannot conduct confidential clinician–patient conversations while shelter-in orders are in effect.

These examples are not intended to minimize the importance of the measures taken to facilitate care in the pandemic. However, they highlight significant informational disadvantages that people with disabilities may experience regarding COVID-19—from prevention (e.g., social distancing) to symptom identification and treatment recommendations. And, while clinicians are often expected to fill patients’

informational gaps, their ability to discharge this responsibility during a pandemic is limited. This difficulty is likely also felt “on the ground.” In a recent survey of (mostly) people with intellectual and mobility disabilities (n = 2469), only 15% ranked health care providers/health systems as the most important source of information about COVID-19.¹⁰

Collaborations with and budgetary allocations for organizations of people with disabilities are critical for promoting high-quality, effective patient care in the pandemic. Currently, such organizations have been impelled to engage in public health activities for which they are not fully prepared or funded. Yet, as organizations with unique expertise in the needs of the populations they serve, they are invaluable players in ensuring better responses to pandemics. Such organizations can assist in developing disability-accessible information about COVID-19 (and future pandemics), admission procedures, and treatment options for a highly diverse population of people with disabilities. Federal, state, and local agencies must also utilize multimodal communication strategies (e.g., text, e-mails, radio, television) to maximize the number of individuals who are informed about the pandemic.¹²

NONDISCRIMINATION AND REASONABLE ACCOMMODATIONS

The prohibition of discrimination on the basis of disability, including the requirements of reasonable accommodations and modifications to ensure equal access to effective health care services, is well established in US and international law.^{14–17} While the requirement of reasonable accommodations and

modifications is not absolute, it aims to ensure that policies, practices, and procedures are inclusive of people with disabilities. Despite improvements, studies show that many health care facilities and medical equipment remain inaccessible, and that health care providers often have insufficient training about the needs of people with disabilities.^{18,19}

Although these systematic deficiencies have resulted in poorer health outcomes among people with disabilities,⁵ the undisputed need for urgent response in the pandemic has exacerbated the challenges. For example, newly constructed alternative care settings may be impossible for blind and low-vision individuals to navigate; the use of nontransparent facial masks prevents lip-reading among some deaf and hard-of-hearing patients; and the no-visitor order for adult patients comes at a time when an accompanying caregiver may be especially needed to facilitate communication and decision-making with some people with intellectual disability.²⁰ Some of these challenges are unavoidable during a pandemic and may not be in violation of the legal requirement for reasonable modifications (e.g., use of alternative care settings). Other challenges, however, could have been addressed with earlier planning, such as acquiring transparent facial masks.

Systemic barriers that have persisted for decades (e.g., inaccessibility of facilities and equipment) cannot be instantly reversed. However, adopting measures to facilitate engagement of patients with disabilities in their care is essential. For example, informed consent processes should take place, as much as possible, through direct conversations with patients and their family members. The already expanded use of telemedicine

options to facilitate communication among clinicians, patients, caregivers, and family members should include disability-friendly accessibility measures that can be downloaded into computers and mobile devices (e.g., remote audiovisual description services for blind and low-vision individuals, captioning or third-party remote connection with American Sign Language interpreter for deaf and hard-of-hearing people).

The requirement of reasonable accommodations and modifications is also key for treatment decisions. A patient with disabilities may require, for example, an extended period of ventilator use for recovery or bed allocation in an established (rather than an ad-hoc) care setting, where accessible equipment is more likely to be available. Classifying patients' usual caregivers as "essential personnel," who are entitled to provide support to hospitalized patients, should also be considered. Certainly, such a classification raises several dilemmas, including the possible risk of infection to caregivers, need for personal protective equipment at a time of shortage, and determining that caregivers are not under undue pressure to risk their own lives to support the individual with disability. However, as attested by the growing number of states that have reversed their no-visit policy for people with disabilities,²⁰ such accommodations allow caregivers to provide indispensable and necessary supports during the pandemic and throughout the admission and hospitalization period. Plain-language forms inquiring about the needs of a patient with disabilities at time of admission to health care facilities,²¹ coordinated efforts with community-based organizations, and consultation with in-house experts (e.g., university disability services) can be instrumental in finding practical solutions and better

addressing the needs of patients and providers with disabilities.

RATIONING

The issue of rationing medical goods and services is a controversial topic in the COVID-19 pandemic. The debate has been particularly relevant for people with disabilities, with several states reportedly having developed triage policies that recommended disability-based exclusion from lifesaving treatments. Washington State, for example, excluded patients with "loss of reserves in energy, physical ability, cognition and general health," while Alabama's (now reversed) policy excluded patients with "severe or profound mental retardation," "moderate to severe dementia," and "severe traumatic brain injury."^{22(p2)} Following complaints filed by disability rights organizations about these emerging discriminatory schemes, the US Department of Health and Human Services' Office for Civil Rights (OCR) issued an instructive bulletin on March 28, 2020, reaffirming the continued application of relevant disability laws in the pandemic to medical decisions relating to people with disabilities.²³ Although reassuring, questions about rationing determinations and disability remain, especially as several similar complaints remain under review.

Rationing requires difficult decisions about allocation of scarce resources under conditions of extreme time pressure and limited data. Ethicists have long considered the values underpinning rationing decisions, and, although maximizing the number of saved lives is commonly the decisive goal,^{24–26} there are varying views about how to operationalize it and balance multiple, competing

ethical and societal values. Another key question is how equality and nondiscrimination on the basis of disability are to be interpreted in rationing decisions.

Part of the challenge is that existing guidelines are often drafted by medical experts with little input from people with disabilities. Whether and how disability perspectives about resource allocation are incorporated into the guidelines is unclear. While the absence of disability voices on such drafting committees may result in unconscious bias²⁷ being introduced into the guidelines, the presence of 1 person with disabilities among many clinicians on such committees may be insufficient to affect the outcomes (as has occurred with some community members serving on institutional review boards²⁸). Inconsistent application and interpretation of existing standards may similarly result in discriminatory outcomes for people with disabilities. For example, New York State's 2015 Ventilator Allocation Guidelines²⁶ (currently under review by the OCR) could be interpreted to allow the removal and reallocation of personal ventilators of people using them regularly if they arrive at a hospital from chronic care facilities and are deemed ineligible for treatment.²⁶ Despite clarification that such an outcome was not intended by the drafters of the guidelines,²⁹ worry is fueled by the absence of a clear, publicly available list of treatment-exclusion criteria and a history of disability discrimination in society, including health care.³⁰

Rationing based on prognosis for survival—a reasonable criterion in a pandemic—similarly raises distress among people with disabilities. Common presumptions of disabilities as implying adverse health outcomes⁵ may result in inaccurate or biased

prognoses. Subjective quality-of-life judgments may similarly enter rationing decisions and result in discriminatory outcomes. Key gatekeepers, including emergency department clinicians, nurses, and medical students, often rate the quality of life of people with disabilities much lower than do the individuals with disabilities themselves, and such biases have an impact on medical futility decisions.³¹

To prevent discrimination, health care facilities should explicitly distinguish between disability status (e.g., deafness and intellectual disability) and comorbidities that have been shown to affect survival (e.g., end-stage cancer) as a criterion for denying lifesaving treatment of COVID-19. They should endorse a clear, unbiased process to assess patients individually, ensuring that allocation decisions are based solely on objective medical evidence for likelihood of survival from COVID-19, rather than on perceived quality of life associated with disability. Transparency in rationing decisions is essential for maintaining public trust in the medical response to this pandemic, particularly given the history of disability discrimination, including the connection between eugenics and the medical profession.

Measures to safeguard against biases erroneously affecting rationing decisions are also needed. As initial assessments of patients are likely to affect subsequent decisions, it is crucial that they be re-evaluated by additional clinicians. Although disability training for clinicians is impractical at this time, educating members of ethics committees (who are likely already involved in the COVID-19 response) and triage committees (if established) and creating diverse, interdisciplinary committees can be helpful. Triage committees are

intended to “buffer” clinicians from the distress over decisions that contravene their patients’ best interests (e.g., ventilator withdrawal) by entrusting “respected clinicians and leaders among their peers and the medical community” with rationing decisions.^{25(p2)}

As regular contact with people with disabilities has been shown to reduce biases, triage committees should include members of health disciplines such as rehabilitation that hold more optimistic views of prognosis and quality of life of patients with disabilities.³² Including health care providers with disabilities, especially those who are also from racial/ethnic minorities, would be similarly invaluable. The prevalence of disabilities is higher among racial/ethnic minorities, and existing (limited) data suggest that health disparities are compounded among people with disabilities who belong to underserved racial/ethnic groups.^{5,6} Moreover, given the high stakes for people with disabilities in rationing decisions, representatives of organizations of people with disabilities or disability rights experts should be consulted in rationing decision-making processes. Although the need for diverse members of triage committees may add complexities, it could facilitate unbiased outcomes and increase trust in the decision-making process.

MOVING FORWARD

As we move from the apex of the pandemic—at least in terms of an initial wave—to its aftermath, marginalized groups such as people with disabilities must be included in future emergency preparedness and implementation efforts.

First, data collection during and after this emergency can inform improvements of national

and local responses to future pandemics. Currently, scarce data are available about disease, recovery, and mortality rates from COVID-19 among people with disabilities. Following media reports of disproportionately high infection and mortality rates in congregate settings, some states in the United States began recording such data. Although still incomplete, accumulated data indicate that, as of May 21, 2020, residents of long-term-care facilities account for 16% of the total cases across 42 states and 42% of the total deaths across 38 states.³³ In addition, a first international study of electronic medical records of COVID-19–positive patients found higher case-fatality rate among people with intellectual disabilities aged 0 to 17 years and 18 to 74 years compared with other patients with COVID-19.³⁴

Yet, it is unknown how many people with disabilities in the United States, with or without chronic underlying conditions associated with COVID-19 such as diabetes, hypertension, lung diseases, and cardiovascular diseases,³⁵ have been sick, died, or recovered from COVID-19. Given the cyclical interaction between poverty and disabilities (including unmanaged chronic conditions⁵) and reports of higher mortality rates from COVID-19 in impoverished neighborhoods and among racial/ethnic minorities,^{35,36} it is further likely that the infection and death toll in the disability community will be high. Collecting and analyzing local and national data that include documented underlying conditions and disability status, aggregated data from treatment decisions, and accurate recording of cause of death (a practice that has been previously found to be compromised with regard to people with intellectual and developmental disabilities who

died from pneumonia³⁷) will allow for developing equitable strategies for health care allocation in future health crises that are supported broadly by multiple constituencies, including those with disabilities.

Second, the need for identifying short- and long-term remedies (i.e., treatment and vaccination) is dire. Fair allocation is similarly necessary. Distributive justice and the societal value of protecting vulnerable populations requires that, after protecting front-line health care and service providers,²⁶ those who are most vulnerable to COVID-19 come next. Although disability status alone would not qualify, rates of chronic medical conditions (e.g., diabetes, cardiovascular disease) associated with worse outcomes of COVID-19 are higher among this population.^{4,5} As people with disabilities are more likely to be insured through public sources,³⁸ state and national governments must ensure that such high-risk individuals, including those who rely on personal care assistants for whom physical distancing is difficult,¹⁰ have access to critical COVID-19 interventions.

Finally, the unique vulnerability of people with disabilities in group homes and residential facilities, psychiatric institutions, nursing homes, and prisons should also be prioritized. Such settings have been shown to be “ground zero” in the COVID-19 pandemic, especially nursing homes with high occupancy of Black/African American and Latino residents.³⁹ The latter findings also highlight the impact of compounded health disparities: individuals (including seniors) from racial/ethnic minorities needing long-term care are more likely than Whites to reside in nursing homes that are overcrowded,³⁹ underfunded,

understaffed, and with poorer quality of care.⁴⁰ The limited and inconsistent guidelines in such facilities regarding visitations, staff screening, and personal protective equipment,³³ and their (in)ability to respond appropriately to COVID-19 is a result of systemic issues that need to be addressed. Future preparedness efforts must focus on increased funding to residential facilities and development of policies to mitigate risks. These include ensuring access to testing, separation of COVID-19 patients from other residents, provision of personal protective equipment for direct care staff, and improved training and support to ensure safe and high-quality implementation of emergency procedures.

The devastation evoked by this pandemic raises challenging bioethical dilemmas that speak to social justice issues that have plagued historically marginalized communities in the United States. The lack of preparedness in providing accessible COVID-19 information, the delayed consideration of the unique health care needs of people with disabilities during the pandemic, and biased policies about allocation of medical goods are reflective of long-term neglect of this population in health care and in society. The pandemic also brings to the fore the dire impacts of compounded health disparities on health outcomes: although the impacts of health disparities are relevant for people with disabilities, as a group, these impacts are especially alarming, and disproportionately high, among people with disabilities from racial and ethnic minorities, including American Indian/Alaska Native communities. Responses to this pandemic should not exacerbate inequities faced by people with disabilities.

There is an urgent need for developing and implementing

immediate measures to address the challenges. Clear guidelines to ensure accurate and comprehensive data recording are essential to inform our next steps. Enhanced consideration of the needs of this large community during the pandemic is necessary to ensure equitable access and treatment in the future. People with disabilities are equally valuable members of our society. Responses to the COVID-19 pandemic should not leave them behind. **AJPH**

CONTRIBUTORS

M. Sabatello conceptualized the article, prepared the initial draft, and revised and finalized the article for submission. T. Blankmeyer Burke, K. E. McDonald, and P. S. Appelbaum provided substantive comments, critical revisions, and edits to the article's drafts. All authors gave final approval of the version to be published.

ACKNOWLEDGMENTS

This work was supported by the National Human Genome Research Institute grants K01HG008653 (M. S.) and RM1HG007257 (P. S. A.).

CONFLICTS OF INTEREST

M. Sabatello is a member of the All of Us Research Program's institutional review board. The authors declare no other conflict of interest.

HUMAN PARTICIPANT PROTECTION

This article is not based on a study involving human participants. Institutional review board approval was not needed.

REFERENCES

- Health Resources and Services Administration, Maternal and Child Health Bureau. *Child Health USA 2014*. Rockville, MD: US Department of Health and Human Services; 2014.
- Disability impacts all of us. 2015. Available at: https://www.cdc.gov/ncbddd/disabilityandhealth/documents/disabilities_impacts_all_of_us.pdf. Accessed April 27, 2020.
- Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *Am J Public Health*. 2015;105(suppl 2):S198–S206.
- Centers for Disease Control and Prevention. Coronavirus disease 2019 (COVID-19). People with disabilities. 2020. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>. Accessed May 24, 2020.

- Yee S, Breslin ML, Goode TD, et al. *Compounded Disparities: Health Equity at the Intersection of Disability, Race, and Ethnicity*. Washington, DC: The National Academies of Sciences, Engineering and Medicine; 2018.
- Blick RN, Franklin MD, Ellsworth DW, Haverkamp SM, Kornblau BL. The double burden: health disparities among people of color living with disabilities. Ohio Disability and Health Program. 2015. Available at: https://nisonger.osu.edu/sites/default/files/u4/the_double_burden_health_disparities_among_people_of_color_living_with_disabilities.pdf. Accessed May 24, 2020.
- Fox MH, White GW, Rooney C, Rowland JL. Disaster preparedness and response for persons with mobility impairments. *J Disabil Policy Stud*. 2007;17(4):196–205.
- Centers for Disease Control and Prevention. 2009 H1N1 flu information for people with disabilities and their caregivers or personal assistants. 2010. Available at: <https://www.cdc.gov/h1n1flu/disabilities>. Accessed May 24, 2020.
- Federal Emergency Management Agency, American Red Cross. Preparing for disaster for people with disabilities and other special needs. 2004. Available at: <https://www.fema.gov/media-library/assets/documents/897>. Accessed April 27, 2020.
- Drum CE, Oberg A, Cooper K, Carlin R. COVID-19 and adults with disabilities: health and health care access online survey summary report. Rockville, MD: American Association on Health and Disability; 2020.
- Federal Emergency Management Agency. Comprehensive Preparedness Guide (CPG) 101 Version 2.0: developing and maintaining emergency operations plans. 2010. Available at: <https://www.fema.gov/media-library/assets/documents/184690>. Accessed April 27, 2020.
- National Council on Disability. Effective communications for people with disabilities: before, during, and after emergencies evaluated. 2014. Available at: <https://ncd.gov/newsroom/2014/05272014>. Accessed April 27, 2020.
- Corrigan PW, Druss BG, Perlick DA. The impact of mental illness stigma on seeking and participating in mental health care. *Psychol Sci Public Interest*. 2014;15(2):37–70.
- Americans With Disabilities Act of 1990, 42 USC § 12101.
- Section 504 of the Rehabilitation Act of 1973, Pub L No. 93-112, 87 Stat 394, codified at 29 USC § 701.
- Patient Protection and Affordable Care Act*, 42 USC § 18001 et seq. (2010).
- Convention on the Rights of Persons With Disabilities*. 13 December 2006, A/RES/61/106, Annex I. Available at: <https://www.refworld.org/docid/4680cd212.html>. Accessed April 27, 2020.
- National Council on Disability. The current state of health care for people with

- disabilities. 2009. Available at: https://www.ncd.gov/rawmedia_repository/0d7c848f_3d97_43b3_bea5_36e1d97f973d.pdf. Accessed April 27, 2020.
- Agaronnik ND, Pendo E, Campbell EG, Ressalam J, Iezzoni LI. Knowledge of practicing physicians about their legal obligations when caring for patients with disability. *Health Aff (Millwood)*. 2019; 38(4):545–553.
- Consortium for Citizens With Disabilities. Sign-on letter: Supporters in hospital administration. 2020. Available at: <http://c-c-d.org/fichiers/Sign-on-letter-supporters-in-hospitals-hospital-admins.pdf>. Accessed May 25, 2020.
- Ballan M, Perri C. *Disability COVID-19 forms*. Stony Brook University. 2020. Available at: <https://you.stonybrook.edu/disabilitycovid19forms/2020/04/08/preparing-individuals-with-intellectual-developmental-disabilities-for-medical-treatment-at-hospitals>. Accessed April 27, 2020.
- Mello MM, Persad G, White DB. Respecting disability rights—toward improved crisis standards of care. *N Engl J Med*. 2020; Epub ahead of print.
- Severino R. BULLETIN: Civil rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19). Department of Health and Human Services' Office for Civil Rights. 2020. Available at: <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>. Accessed April 27, 2020.
- Emanuel EJ, Persad G, Upshur R, et al. Fair allocation of scarce medical resources in the time of Covid-19. *N Engl J Med*. 2020;382(21):2049–2055.
- Troeg RD, Mitchell C, Daley GQ. The toughest triage—allocating ventilators in a pandemic. *N Engl J Med*. 2020;382(21):1973–1975.
- New York State Task Force on Life and the Law. Ventilator allocation guidelines. 2015. Available at: https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf. Accessed April 27, 2020.
- Aaberg VA. A path to greater inclusivity through understanding implicit attitudes toward disability. *J Nurs Educ*. 2012;51(9):505–510.
- Klitzman R. Institutional review board community members: who are they, what do they do, and whom do they represent? *Acad Med*. 2012;87(7):975–981.
- Fins JJ. New York State Task Force on Life and the Law Ventilator Allocation Guidelines: how our views on disability evolved. The Hastings Center Bioethics Forum. 2020. Available at: <https://www.thehastingscenter.org/new-york-state-task-force-on-life-and-the-law-ventilator-allocation-guidelines-how-our-views-on-disability-evolved>. Accessed May 24, 2020.
- Ne'eman A. Opinion: I will not apologize for my needs. *New York*

- Times*. March 23, 2020. Available at: <https://www.nytimes.com/2020/03/23/opinion/coronavirus-ventilators-triage-disability.html>. Accessed May 24, 2020.
- National Council on Disability. Medical futility and disability bias. 2019. Available at: <https://ncd.gov/publications/2019/bioethics-report-series>. Accessed May 24, 2020.
- Cushman DM, Thomas K, Mukherjee D, Johnson R, Spill G. Perceived quality of life with spinal cord injury: a comparison between emergency medicine and physical medicine and rehabilitation physicians. *PM R*. 2015;7(9):962–969.
- Kaiser Family Foundation. State data and policy actions to address coronavirus. 2020. Available at: <https://www.kff.org/health-costs/issue-brief/state-data-and-policy-actions-to-address-coronavirus>. Accessed May 25, 2020.
- Turk MA, Landes SD, Formica M, Goss KD. Intellectual and developmental disability and COVID-19 case-fatality trends: Trinetx analysis. *Disabil Health J*. 2020; Epub ahead of print.
- Garg S, Kim L, Whitaker M, et al. Hospitalization rates and characteristics of patients hospitalized with laboratory-confirmed coronavirus disease 2019—COVID-NET, 14 states, March 1–30, 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(15):458–464.
- Buchanan L, Patel JK, Rosenthal BM, Singhvi A. A month of coronavirus in New York City: see the hardest-hit areas. *New York Times*. April 1, 2020. Available at: <https://www.nytimes.com/interactive/2020/04/01/nyregion/nyc-coronavirus-cases-map.html>. Accessed May 25, 2020.
- Landes SD, Stevens D, Turk MA. COVID-19 and pneumonia: increased risk for individuals with intellectual and developmental disabilities during the pandemic. Lerner Center for Public Health Promotion. 2020. Available at: https://lernercenter.syr.edu/wp-content/uploads/2020/04/Landes.Stevens.Turk_.pdf. Accessed May 25, 2020.
- Kennedy J, Wood EG, Frieden L. Disparities in insurance coverage, health services use, and access following implementation of the Affordable Care Act: a comparison of disabled and nondisabled working-age adults. *Inquiry*. 2017;54:46958017734031.
- Gebeloff R, Ivory D, Richtel M, et al. The striking racial divide in how Covid-19 has hit nursing homes. *New York Times*. May 21, 2020. Available at: <https://www.nytimes.com/article/coronavirus-nursing-homes-racial-disparity.html>. Accessed July 7, 2020.
- Konetzka RT, Werner RM. Disparities in long-term care: building equity into market-based reforms. *Med Care Res Rev*. 2009;66(5):491–521.