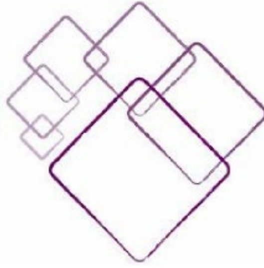

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Q&A

Securing Compliance With, And Enforcement Of, Crisis Standards Of Care

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Q. Our State has finally developed Crisis Standards of Care (CSC) which broadly reflect the directives and resolutions of the HHS Office of Civil Rights (OCR). However, there seems to be no State oversight of hospitals' compliance with these standards in their own triage plans and protocols. Nor is there any effort to ensure that facilities are prepared to implement these plans if necessary. What strategies can we use to ensure State CSC guidance is being followed, and to respond in the event that individuals with disabilities are subject to discrimination or other unequal treatment if crisis standards are invoked?

A. P&As have been rightly focused on securing nondiscriminatory CSCs in their States. However, as illustrated by the recent crisis in Los Angeles County, even the best State guidelines are of limited use when they are not adhered to by individual hospital systems, or when facilities and staff are not prepared to implement those standards in a consistent way. The urgency of these issues demands a multi-pronged advocacy approach, involving state oversight agencies, hospital and trade associations, engagement with state legislators and media outlets, and outreach and education to individuals and stakeholders. Establishing direct lines of communication with hospital legal counsel and state Attorneys' General may help P&As to diffuse emergent and time-sensitive crises, but legal tools to combat discrimination by State and private entities should be part of any larger strategy to avoid and remedy discrimination in access to life-saving care.

I. Introduction

Early in the pandemic, the U.S. Department of Health and Human Services' Office of Civil Rights (OCR) issued a bulletin directing that "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."[1] Despite this guidance, states began publishing or resurrecting CSCs that explicitly or implicitly discriminated against disabled individuals, as well as those with pre-existing conditions or comorbidities, including older adults and people of color. Individuals with certain diagnoses, who needed hands-on assistance for activities of daily living, or who faced shorter life expectancies due to health care inequities and underlying disability, found themselves excluded from or deprioritized for lifesaving treatment in the event of health care rationing.[2]

Most State CSCs failed to acknowledge, or guard against, the unconscious bias that leads to the devaluing of people with disabilities, and to misinformed assumptions about their quality of life.[3] States also failed to consider what reasonable accommodations would be required to ensure disabled individuals could communicate their symptoms, provide informed consent, and participate in their care and treatment.[4] These violations prompted P&As across the country to engage in advocacy with their State administrations,[5] and led to more than ten OCR complaints.[6] For those P&As who have not yet reviewed and, where necessary, challenged discriminatory CSCs, doing so should be a top priority.

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[1] *See* HHS Office of Civil Rights, BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), March 28, 2020, available at https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf

[2] *See, e.g.*, OCR Complaints filed in Washington State, Alabama, and Tennessee, available at https://www.centerforpublicrep.org/covid-19-medical-rationing/.

[3] These issues were effectively resolved in many CSC revisions thanks to advocacy from the P&A community. *See, e.g.* revised California SARS-CoV-2 Pandemic Crisis Care Guidelines at 16-17 (plans should be designed to "ensure that no one is denied care based on stereotypes, assessments of quality of life, or judgments about a person's 'worth' based on the presence or absence of disabilities or other factors…"Treatment allocation decisions cannot be made based on misguided assumptions that people with disabilities experience a lower quality of life or that their lives are not worth living."), available at https://www.cidrap.umn.edu/sites/default/files/public/php/258/258_hospitals.pdf

[4] More than 35 state advocacy organizations, including P&As, sent letters to their Governors and responsible public health agencies regarding the need for nondiscriminatory crisis standards of care, including reasonable accommodations to the triage process. These letters, and an overview of state level advocacy, can be found at https://www.centerforpublicrep.org/covid-19-medical-rationing/.

[5] Letters from P&As to State Governors and administrative agencies and shared with CPR are available at https://www.centerforpublicrep.org/covid-19-medical-rationing/.

[6] OCR complaints that have been successfully resolved now include Texas, North Carolina, Utah, Tennessee, Connecticut, Pennsylvania, and Alabama. Copies of these complaints, related press releases, and links to revised crisis standards and reasonable accommodation policies also can be found at https://www.centerforpublicrep.org/covid-19-medical-rationing/.

Advocacy efforts by P&As and their partners, supported by evaluation frameworks from national disability organizations[7] and OCR resolutions, helped to guide significant CSC reforms. Most recently, the National Academy of Medicine, in collaboration with OCR, issued recommendations on implementation of crisis standards, including key principles for the development of non-discriminatory triage protocols.[8] However, despite significant progress in this area, the work of ensuring equitable application of CSCs is far from over.

Crisis standards are only one of many ways in which the nation's pandemic response laid bare a health care system long plagued by discrimination and bias towards people with disabilities. State CSCs illustrated the need to confront and challenge these inequities,[9] as well as age and race discrimination,[10] and to identify remedies that would begin to unwind the structural inequalities that impede equal access to quality health care services. The most effective P&A strategies and responses to CSCs will integrate this understanding of intersectional discrimination.

As States works to avoid invocation of crisis standards, and to implement equitable vaccine allocation and distribution strategies, it is increasingly important for P&As to: 1) actively monitor hospitals' compliance with State CSC guidelines; 2) engage responsible entities to ensure compliance with their legal obligations; 3) elevate CSC implementation issues among advocates, legislators and the media; 4) educate, inform, and represent affected individuals when their rights are violated; and 5) develop litigation and other systemic responses where necessary to ensure people with disabilities receive equal access to lifesaving medical care.

II. Strategies for Securing Implementation of Statewide Crisis Standards

Even equitable CSC guidelines may not translate into equitable care and triage decision-making. Active monitoring of individual hospitals, and a robust system of State

[7] *See, e.g.,* EVALUATION FRAMEWORK FOR CRISIS STANDARD OF CARE PLANS, last updated November 30, 2020, available at https://www.centerforpublicrep.org/wp-content/uploads/Updated-evaluation-framework.pdf; EVALUATION FRAMEWORK FOR HOSPITAL VISITOR POLICIES, last updated June, 2020, available at https://www.centerforpublicrep.org/wp-content/uploads/Disability-Org-Guidance-on-COVID-19-Hospital-Visitation-Policies_5-14-20_Final.pdf.

[8] National Organizations Call for Action to Implement Crisis Standards of Care During COVID-19 Surge Dec 18, 2020, available at https://nam.edu/national-organizations-call-for-action-to-implement-crisis-standards-of-care-during-covid-19-surge/.

[9] *See e.g.*, *Crisis Standards of Care in the USA: A Systematic Review and Implications for Equity Amidst COVID-19* Emily C. Cleveland Manchanda, Charles Sanky and Jacob M. Appel, available at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7425256/pdf/40615_2020_Article_840.pdf.

[10] *See, e.g.,* Civil Rights Protections Prohibiting Race, Color and National Origin Discrimination During COVID-19" HHS Office of Civil Rights, July 20, 2020, available at https://www.hhs.gov/sites/default/files/title-vi-bulletin.pdf; Double Jeopardy: COVID-19 and Behavioral Health Disparities for Black and Latino Communities in the U.S., SAMSHA (Submitted by OBHE), available at covid19-behavioral-health-disparities-black-latino-communities.pdf.

oversight and accountability are crucial to ensure: 1) that facilities' have developed standards that are consistent with State CSCs; 2) that hospital standards are publicly available, including any provisions detailing patient appeal procedures; and 3) that hospital staff are trained to consistently and accurately implement those standards – before that implementation becomes necessary. The list of proposed strategies below provides a starting point for P&As to engage with their partners in CSC development and enforcement, and to expand the impact of their collective efforts.

Continue direct advocacy with state administrative and public health agencies. Many P&As built broad coalitions that include racial justice organizations, civil rights advocates, and organizations serving aging adults and cross-disability groups as part of their advocacy on CSC development and reform. Together with these coalitions, they should communicate directly with state officials responsible for the creation of crisis standards, and insist on aggressive oversight of medical facilities to ensure compliance with these standards, based upon the administrative agency's licensing, oversight, and funding responsibilities, and State of Emergency orders which may afford government entities additional authority to require hospital compliance.[11]

Engage with allied medical professionals, hospital and trade associations. Many emergency room physicians, medical ethicists, and other health care professionals have been outspoken critics of discriminatory crisis standards,[12] and have successfully advocated for non-discrimination provisions, clearer allocation criteria, specialized training, and more diversity within triage teams and the committees that oversee their work. Building connections to, and directly partnering with local health care professionals can add credibility to ongoing advocacy efforts, afford access to relevant medical expertise, and provide important, internal perspectives on how plans to prepare for the invocation of crisis standards are proceeding.

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[11] For example, Pennsylvania's CSC appeals process refers unresolved complaints to the State Department of Public Health. See Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines, April 10, 2020, available at https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID-19%20Interim%20Crisis%20Standards%20of%20Care.pdf (also noting on p. 46 that "[t]he improper execution of these standards would constitute a serious breach of conduct by the providers.").

[12] *See. e.g., Non-Discrimination in the Stewardship and Allocation of Resources During Health System Catastrophes Including COVID-19*, the American College of Physicians, available at https://www.acponline.org/acp_policy/policies/acp_policy_on_nondiscrimination_in_the_stewardship_of_healthcare_resources_in_health_system_catastrophes_including_covid-19_2020.pdf; *American Academy of Developmental Medicine and Dentistry, Ventilator Policy Statement* (Updated May 2020), available at https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5ecfb6fff13530766aeae51a/1590671105171/Ventilator+-+Policy+Statement+w+Addendum.pdf; Catherine L. Auriemma, et al., *Eliminating Categorical Exclusion Criteria in Crisis Standards of Care Frameworks*, Am. J. of Bioethics 1(2020)("Even when purportedly 'objective' criteria are employed to allocate health care resources, subjective notions of the quality or desirability of life with disabilities may play an influential role. These negative biases and assumptions often result in the devaluing of the lives of people with disabilities which contributes to health care inequities and discrimination in multiple sectors of society.").

Similarly, statewide hospital associations have played an important role in coordinating and implementing medical facilities' COVID-19 response. These associations have a vested interest in their members' reputation, and their preparation for invoking crisis standards in a responsible, credible, and equitable manner. They may be willing to work together to resolve challenges to the development and implementation of CSCs, be they resource disparities between rural and urban facilities, access to specialized staff and clinical resources, or the need to identify new training curriculums on disability and implicit bias. Finally, as part of monitoring constituents' access to care during the pandemic, P&As should consider outreach to hospital taskforces, patient advocates, patient/family councils, ADA coordinators, or others working on issues of diversity, equity and inclusion or the provision of reasonable accommodations in these settings.

Outreach to key legislators. Many P&As worked with their state and local legislators to elevate issues of health equity and discriminatory crisis standards early in the pandemic. Involving key legislators in ongoing advocacy around implementation of CSC guidelines, including Black and Latino caucuses, and the chairs of committees focused on public health, aging and disability can bring additional pressure to bear on State entities which may assume invocation of CSCs is unlikely, or which are focused on the logistics of vaccine distribution.

Provide information to individuals and stakeholder organizations. Given the multitude of issues and concerns facing individuals and families during the pandemic, P&A constituencies may not be familiar with the nuances of triage protocols, or the range of accommodations available to avoid discriminatory outcomes. For these reasons, several P&As have developed Know You Rights resources providing actionable information on crisis standards and the kinds of reasonable accommodations that facilities may be obligated to provide, including access to designated support persons.[13] These resources can be part of an information and education campaign involving other self-advocacy and family organizations. They also should contain information on who to call for individual assistance and advice.

III. Responding to Evidence of Disability Discrimination under Crisis Standards of Care

[13] *See. e.g.,* Health Care Rationing and Accommodations: What Massachusetts Patients with Disabilities Need to Know During the COVID-19 Pandemic, CPR and the Disability Law Center, available at https://www.centerforpublicrep.org/news/cpr-releases-updated-know-your-rights-resource-on-crisis-standards-of-care/; Support While Seeking Medical Treatment for COVID-19: The Rights Of Patients with Disabilities, Disability Rights Pennsylvania, available at V3-Hospital-visitation.pdf (disabilityrightspa.org).

Most State CSCs have been issued as guidelines to health care providers in the event crisis standards of care are invoked.[14] Although there is considerable pressure on facilities to adopt State standards as further insulation from liability or allegations of discriminatory care and treatment, whether and how these standards can be successfully enforced presents significant issues that will vary depending on a number of factors. Relevant considerations include: 1) the authority under which the CSCs were issued;[15] 2) the power of state agencies over the medical facilities that implement the CSCs;[16] and 3) the ability under state law to challenge the agency or entity which issued the CSCs.[17]

Another factor to consider is the mandatory versus optional nature of the CSCs, and even various provisions within CSCs themselves.[18] Some State CSCs contain key principles,[19] or core components,[20] which must be included in all hospital CSCs.

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[14] At least one CSC was issued by Executive Order. In April 2020, Colorado Governor Jared Polis used the authority of his office, and the Colorado Disaster Emergency Act, 24 - 33.5 - 704(5) et seq., to approve state-wide Crisis Standards of Care as an Annex to the Colorado Dept. of Public Health and Environment's, All Hazards Internal Emergency Response and Recovery Plan, (updated December 2020), available at https://cdphe.colorado.gov/colorado-crisis-standards-care.

[15] While most recent CSCs were promulgated pursuant to emergency declarations concerning the pandemic, many were also authorized by state licensing, regulatory, and health care authorities.

[16] State public health agencies often have broad authority under state law to oversee and regulate practices in licensed health care facilities. Other state bodies, such as pandemic task forces, may have only advisory capacities. In Texas, the CSC were recently issued by the Southwest Texas Regional Advisory Council, which has legal authority under state law to require certain medical practices for all health care facilities in the San Antonio region, while similar guidelines were issued by the North Texas Mass Critical Care Guidelines Task Force, which has only advisory authority for similarly-situated facilities in the Dallas region.

[17] Whether there is a private right of action or third-party beneficiary claim to enforce an agency requirement is uniquely a matter of state law.

[18] For instance, the Massachusetts CSC were advisory in nature, leaving hospital or medical facilities discretion in determining whether to adopt the same, similar, or different provisions in their individual guidelines. However, the Massachusetts CSC also required that certain key elements be present in every facility CSC. *See* fn. 17, *supra*. The public health agency which issued the CSCs also required that every facility post its guidelines on its website.

[19] *See* Oregon Health Authority, Principles in Promoting Health Equity During Resource Constrained Events, December, 2020. This interim guidance for CSC development is available at https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le3513.pdf.

[20] For example, Massachusetts' CSC (revised in October 2020) contains the following mandatory provisions:

> Each healthcare institution may modify its specific triage processes based on its particular resources and circumstances, but each institution's specific process must adhere to the core triage principles set out in this document. These include: 1) creation of a triage team to separate triage decisions from bedside clinical decisions; 2) use of a critical care allocation framework that incorporates the scoring system and prioritization categories laid out in this document; 3) reassessment of patients receiving critical care with reallocation of resources where appropriate; 4) a commitment to the principle that allocation decisions should not consider characteristics that have no bearing on the likelihood or magnitude of benefit; 5) reasonable accommodations for people with disabilities; and 6) incorporation of an appeals process for the mathematical calculation of an initial priority score or a decision to withdraw life-sustaining treatment over the objection of a patient or surrogate.

Further complicating legal enforcement strategies are liability protections – both those existing in state and federal law, and those ordered (or planned) in response to the pandemic.[21] Finally, there are the practical and legal consequences associated with the actual invocation of crisis standards, and the ways in which specific physician and hospital duties to care may be altered, or carried out in modified ways, under these circumstances.[22]

For most individuals and families needing emergent and potentially life-saving care during the invocation of crisis standards, time is of the essence. P&As should develop methods for the prompt identification and urgent triage of incoming calls related to the discriminatory application of crisis standards, or denials of reasonable accommodations by treating hospitals. P&As should develop scripts for use by intake staff, identify community resources for referrals, and prepare strategies and options for individual advocacy – all of which will expedite program responses. Establishing direct lines of communication with hospital legal counsel and state Attorneys' General, may help elevate and informally resolve the time-sensitive crises of individual constituents. Where State CSCs require individual facilities to have expedited appeal procedures, P&As should train staff to navigate these procedures with individuals and their agents/family members. Finally, P&As can exercise their authority to investigate allegations of abuse and neglect, or the reported death of individuals with disabilities, using their federal statutory authority.[23]

Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic, available at https://www.mass.gov/doc/crisis-standards-of-care-draft-planning-guidance-for-public-comment-october-6-2020/download.

[21] "On March 10, 2020, HHS Secretary Azar issued a declaration pursuant to the Public Readiness and Emergency Preparedness Act ("PREP Act") to provide liability immunity for certain activities related to medical countermeasures against COVID-19. Immunity extends to individuals and entities that manufacture, distribute, administer, prescribe, or use "Covered Countermeasures" against claims of loss caused by, arising out of, relating to, or resulting from the manufacture, distribution, administration of use of Covered Countermeasures, except for claims involving "willful misconduct." Covered Countermeasures include "qualified pandemic or epidemic products" and drugs, biological products, or devices authorized for emergency use in connection with COVID-19." *The Coronavirus Crisis—The Impact of Federal Liability Immunity, Waivers, and Guidance on Health Care Providers*, Jones Day, March 2020, https://www.jonesday.com/en/insights/2020/03/coronavirus-guidance-on-health-care-providers.
The Health, Economic Assistance, Liability Protection and Schools (HEALS) Act, as proposed by the Senate, would provide broad immunity from liability for harm related to COVID-19 for any business, non-profit, school, medical provider, or medical professions. More information about pending COVID-19 legislation can be found at https://medicaid.publicrep.org/feature/covid-19-legislation/.

[22] Intersections between the American Medical Associations Code of Medical Ethics and crisis situations where extreme scarcity and insufficient medical resources exist are discussed at https://www.ama-assn.org/delivering-care/ethics/crisis-standards-care-guidance-ama-code-medical-ethics.

[23] P&As' also have authority to access records without individual consent in certain circumstances, including abuse and neglect investigations (45 C.F.R. § 1326.25(a)(3); 42 C.F.R. §51.41(b)(2)(iii)); following a disabled person's death (45 C.F.R. §1326.25(a)(5); 42 C.F.R. §51.41(b)), or when an individual's health and safety is believed to be in immediate jeopardy. See, 45 C.F.R. § 1326.25(a)(4); 42 C.F.R. §51.41(b)(3). If using these authorities to access records, as opposed to specific consent, P&As

More formal legal tools to combat discrimination by State and private entities should also be part of any larger strategy to avoid and remedy discrimination in access to life-saving care, especially to the extent noncompliance with CSCs is widespread, or directly related to failures by responsible State oversight or licensing agencies.[24] Direct enforcement actions against State licensing or regulatory agencies may be possible, depending on the authority under which the CSCs were adopted, the agency directives to covered medical facilities, and the scope of general enforcement authorities of the State agency. As many State P&As have seen, OCR complaints, and even the threat of their submission, can also convince recalcitrant State agencies (and individual facilities) to modify problematic CSCs, and to address allegations of the inappropriate application of triage decisions.

To the extent there is time and opportunity to pursue individual legal actions against private entities for the failure to implement non-discriminatory crisis standards, there are a range of federal laws available. Title III of the ADA prohibits places of public accommodation from denying qualified individuals the equal enjoyment of their goods, services and facilities, providing separate or unequal benefits, or failing to make reasonable modifications in policies, practices, or procedures, unless such modifications would result in a fundamental alteration.[25] Under Section 504 of the Rehabilitation Act, individuals may not be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance, including those principally involved in the business of health care.[26] Section 1557 of the ACA also provides that no health program or activity that receives federal funds, nor any program or activity administered or established under Title I of the ACA, may discriminate against a person protected by Section 504.[27]

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must maintain specific confidentiality obligations that limit their ability to subsequently disclose those records. See, e.g., 42 C.F.R. §51.45(a)(1)(i); 45 C.F.R. § 1326.28(a); 42 U.S.C. §10806(a); 42 CFR 51.45. For more information on these considerations, see NDRN's overview of legal authorities supporting P&A access, and links to its access manual and case docket, available at https://www.tascnow.com/resource/legal-grounds-for-access-under-the-pa-acts-and-regulations/.

[24] Title II of the ADA prohibits public entities from excluding people with disabilities from their programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Implementing regulations promulgated by the United States Department of Justice (DOJ) define unlawful discrimination under Title II to include, inter alia: using eligibility criteria that screen out or tend to screen out individuals with disabilities, failing to make reasonable modifications to policies and practices necessary to avoid discrimination, and perpetuating or aiding discrimination by others. 28 C.F.R. §§ 35.130(b)(1)-(3), 35.130(b)(7)-(8).

[25] 42 U.S.C. § 12182; *see also*, 42 U.S.C. § 12181(7)(F); 28 CFR § 36.201.

[26] 29 U.S.C. § 794.

[27] 42 U.S.C. § 18116; 45 C.F.R. § 92.2(b)(4). Note that the continuing viability of these and other provisions of the Affordable Care Act are currently before the Supreme Court in *California v. Texas*, No. 19-840, https://www.supremecourt.gov/search.aspx?filename=/docket/docketfiles/html/public/19-840.html. The case has been consolidated with *Texas v. California*, No. 19-1019. *See also*, *Texas v. U.S.,* No. 19-10011, slip opin. (5th Cir. Dec. 20, 2019). Oral arguments were held in November of 2020.

Finally, P&As should consider whether state anti-discrimination or public accommodation laws provide additional remedies. State probate or guardianship courts often enforce state statutory or common law protections concerning the withdrawal or denial of life-saving treatment. Substituted judgment procedures and related due process protections for individuals alleged to be incapacitated may offer an additional means of protecting against premature medical decisions to withhold or withdraw life-saving treatment, as well as decisions that do not reflect the wishes and preferences of the patient.[28] Partnering with legal services programs and supporting public entities who are appointed as counsel in these situations can further extend the reach of P&A advocacy.

IV. Conclusion

Given increasing COVID-19 infection rates around the country, new and more contagious mutations of the virus, diminished staff capacity within hospitals, and the number of jurisdictions who have already come close to, or needed to invoke crisis standards, it is critical that States are prepared for, and able to consistently implement these guidelines. While working to promote vaccination and avoid the need for crisis standards, P&As must also ensure that their State has adopted non-discriminatory CSCs, and then actively monitor compliance with these standards. A multi-pronged approach, involving direct advocacy with state oversight agencies, collaboration with hospital and trade associations, engagement with state legislators, outreach to individuals and stakeholder organizations, and litigation remedies should be part of any larger strategy to address discrimination in access to life-saving care

[28] *See, e.g.,* Massachusetts Probate Code, G.L. c. 190B, Sec. 5-306A which reads: “No guardian, temporary guardian or special guardian of a minor or an incapacitated person shall have the authority to consent to treatment for which substituted judgment determination may be required, provided that the court shall authorize such treatment when it (i) specifically finds using the substituted judgment standard that the person, if not incapacitated, would consent to such treatment and (ii) specifically approves and authorizes a treatment plan and endorses said plan in its order or decree. The court shall not authorize such treatment plan except after a hearing for the purpose of which counsel shall be provided for any indigent minor or incapacitated person.”