TASC Training & Advocacy Support Center

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# Challenging Discrimination in Allocating Life-Saving Treatment: An Evolution from Disability to Intersectionality

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**Q:** We are considering challenging the discriminatory allocation of life-saving treatment during a pandemic, as provided in our Crisis Standards of Care (CSC). What are possible approaches and the most effective strategies to require states and hospitals to revise these CSCs?

**A:** Advocacy should address the discriminatory impact of the CSC on all marginalized populations, including persons with disabilities, older adults, people of color, incarcerated persons, immigrants, and other disenfranchised groups. P&As should engage a broad coalition of organizations representing these populations, assess the CSC for intersectional issues, and develop revisions to the CSC that address both explicit and implicit discrimination, and the impact of health inequities. P&As should employ a wide range of strategies including negotiation with governmental officials, complaints to the Department of Health and Human Services' (HHS) Office of Civil Rights (OCR), media and legislative advocacy, and direct action.

## I. Introduction

Many states have confronted the threat of medical rationing since the escalation of the COVID-19 pandemic in the United States. At the same time, the pandemic has served to highlight racist practices and policies that result in glaring health inequities. As the impact of the pandemic has become measurable, it has become clear that the illness is resulting in a disproportionate impact on Black, Indigenous, People of Color (BIPOC) communities.[1] Similarly, people with disabilities are more vulnerable to healthcare inequity during the pandemic through various rationing schemes.[2] Critically, disability is

[1] Richard A. Oppel, Jr. et al., *The Fullest Look at the Racial Inequity of Coronavirus*, N.Y. TIMES (July 5, 2020), https://www.nytimes.com/interactive/2020/07/05/us/coronavirus-latinos-african-americans-cdc-data.html.
[2] *See, e.g.*, Andrew Pulrang, *The Disability Community Fights Deadly Discrimination Amid the COVID-19 Pandemic,* FORBES (Apr. 14, 2020),

inherently intersectional. The CDC estimates that 26% of the U.S. population lives with a disability, and that specifically, 2 in 5 adults over 65, 25% of women, and 2 in 5 non-Hispanic American Indians or Alaska Natives live with disabilities.[3] Therefore, people with disabilities who live at these intersections may face discrimination on the basis of their disability, race, gender, age, and/or other marginalized identity. Advocacy to combat discrimination in allocating life-saving treatment and providing crisis care must recognize multiple identities and how the intersections of these identities compound health disparity.

## II. The Evolution of Advocacy Challenging CSC.

The COVID-19 pandemic demonstrates how entrenched discrimination is within social structures and health care policies. Over the course of the pandemic, advocacy on CSC has evolved from the earliest complaints, which responded to explicit, narrowly-defined discrimination, to intersectional coalition-based responses to both explicit and implicit discrimination. The more recent, broader approaches have increased the impact and effectiveness of challenges to discriminatory policies, and have generated coalitions to address intersectional issues even beyond CSC. This evolution is evidenced in the approaches of three states that effectively challenged discriminatory CSC.[4]

### a. Alabama

Advocates in Alabama were some of the first to respond to the looming discriminatory rationing schemes. Alabama's CSC, called "Criteria for Mechanical Ventilator Triage Following Proclamation of Mass-Casualty Respiratory Emergency," (Criteria), were drafted in 2009 and revised in 2010.[5] The Criteria required that in the event of ventilator shortages, hospitals not offer ventilators to patients with various disabilities, specifically singling out "people with severe or profound mental retardation, moderate to severe dementia, and severe traumatic brain injury."[6] In response, the Alabama Disability

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https://www.forbes.com/sites/andrewpulrang/2020/04/14/the-disability-community-fights-deadly-discrimination-amid-the-covid-19-pandemic/#2655cd5a309c.

[3] Disability Impacts All of Us, CDC, https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html; Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults, CDC: MMWR (Aug. 17, 2018), https://www.cdc.gov/mmwr/volumes/67/wr/mm6732a3.htm?s_cid=mm6732a3_w (racial breakdown of any disability is: 16.3% white, 18.1% Black, 17.6% Hispanic, 27.7% AI/AN, 7.2% Asian, 24.9% other).

[4] For a list of issues raised in these challenges, and a method for analyzing CSC, *see CPR and Partners Issue Framework to Assist Stakeholders in Evaluating Rationing Plans* (Apr. 9, 2020), available at https://www.centerforpublicrep.org/news/cpr-and-partners-issue-framework-to-assist-stakeholders-in-evaluating-rationing-plans/.

[5] *See* Connor Sheets, *'Last Resort': Alabama's Plan for Deciding which Coronavirus Patients Get Ventilators*, AL.COM (Mar. 26, 2020), https://www.al.com/news/2020/03/last-resort-alabamas-plan-for-deciding-which-coronavirus-patients-get-ventilators.html; Criteria available at https://adap.ua.edu/uploads/5/7/8/9/57892141/alabamas_ventilator_rationing_plan.pdf.

[6] Complaint at 2, available at https://www.centerforpublicrep.org/wp-content/uploads/2020/03/AL-OCR-Complaint_3.24.20.docx.pdf (internal quotations omitted).

Advocacy Program (ADAP), supported by several national disability organizations, filed a complaint with OCR on March 24, 2020 that challenged the express discrimination against individuals with intellectual and related neurological disabilities.

ADAP's complaint was one of the first filed, before the additional intersectional concerns surrounding the pandemic's impact became measurable. It focused on explicit discrimination against certain individuals with disabilities. It was brought solely by the P&A, and national disability organizations, rather than a broad, intersectional coalition. Given its facial discriminatory criteria, OCR quickly resolved the complaint through its voluntary resolution process, after concluding that the policy was discriminatory on the basis disability and age.[7] Alabama has since removed the discriminatory policy and is operating under more general CSC,[8] but the P&A has demanded further revisions under a strategy that now includes a more intersectional approach.[9]

**b. Massachusetts**

In the early phase of the pandemic, Massachusetts had one of the highest rates of COVID-19 in the country. This raised a real concern, amongst state officials and the medical community, that it might be necessary to invoke CSC. The State convened a task force, primarily comprised of public health experts and physicians from the major Boston hospitals to update its guidelines drafted in 2007 called "Massachusetts Draft Guidelines for the Development of Altered Standards of Care for Influenza Pandemic." Disability advocates were quick to respond to the threats of medical rationing of life-saving treatment under these CSC. A coalition of primarily disability-focused and legal services organizations, led by the CPR, sent a letter to the administration emphasizing the increased risk of infection to those living in congregate settings, and the need to ensure equal access to life-saving treatment to these populations.[10]

When the first COVID-19-specific CSC was released on April 7, 2020, CPR intentionally broadened its coalition partners to include organizations from broad and varied

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[7] *OCR Reaches Early Case Resolution with Alabama After it Removes Discriminatory Ventilator Triaging Guidelines*, HHS Press Office (Apr. 8, 2020), available at https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html. The resolution references the March 28, 2020 OCR Bulletin finding that civil rights laws are still in effect during the pandemic and OCR will continue to enforce them, available at https://www.hhs.gov/about/news/2020/03/28/ocr-issues-bulletin-on-civil-rights-laws-and-hipaa-flexibilities-that-apply-during-the-covid-19-emergency.html.

[8] *See Alabama Crisis Standards of Care Guidelines* (Feb. 28, 2020), available at https://www.adph.org/CEPSecure/assets/alabamacscguidelines2020.pdf.

[9] ADAP April 22, 2020 letter available at, https://adap.ua.edu/uploads/5/7/8/9/57892141/adap_letter_to_gov_4.22.20.pdf.

[10] Massachusetts Mar. 26, 2020 letter available at, https://www.centerforpublicrep.org/news/cpr-and-local-partners-send-letter-to-governor-on-need-for-statewide-guidelines-preventing-discriminatory-allocation-of-life-saving-medical-care/.

constituencies to address both the implicit and explicit discrimination within the CSC.[11] Massachusetts and national advocates with shared interests and concerns united to work intersectionally. First, in a letter to the Massachusetts Health & Hospital Association (MHA), advocates identified the aspects in triage that were discriminatory against people with disabilities, older adults, and communities of color.[12] There were two critical and novel factors that provided the impetus for this expanded coalition: (1) pressure from Black and brown state and national legislators who identified the discriminatory impact of the CSC on communities of color and (2) advocacy by physicians and other health care providers who focused on the health equities that animated these CSC. CPR and its partners drafted a formal OCR complaint, but decided to first offer the State an opportunity to revise the CSC, with the explicit understanding that a complaint would be filed if the response was unsatisfactory.[13]

Jon Santiago, an emergency medicine physician and a Massachusetts House Representative, along with other committed physicians organized the Massachusetts Coalition for Health Equity. Representative Santiago, on his own and in collaboration with U.S. Representative Joe Kennedy, III, publicly and effectively highlighted the implicit racial discrimination in the CSC.[14] Similarly, the Massachusetts Black and Latino Legislative Caucus sought increased testing, a COVID-19 diversity taskforce, and revocation of the standards.[15] U.S. Representative Ayanna Pressley sent a letter to the administration emphasizing the disparate racial impact the pandemic was having and the added dangers posed for disabled individuals.[16] The Public Health Committee

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[11] *See Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic* (Apr. 7, 2020) (the implicitly discriminatory CSC policies focused on life-year prioritization, non-modified SOFA scores, and lowering priority scores based on presence of comorbid conditions).

[12] Apr. 11, 2020 letter to MHA at 1, available at, https://www.centerforpublicrep.org/wp-content/uploads/2020/04/MA-Advocates-follow-up-letter-to-hospitals.MMS_.4.11.20-1.pdf.("among the most problematic aspects of the proposed triage process are its consideration of 'life-limiting comorbidities' and 'long term prognosis' in the scoring process").

[13] CPR reframed the complaint as a letter, in order to afford state officials a preview of the allegations of discrimination that would be presented to OCR. *See* CPR Letter to Baker Administration, available at https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Ltr-Admin-on-revised-MA-CSC.4.22.20.final_-1.pdf.

[14] *See* Jon Santiago (@IamJonSantiago), TWITTER, https://twitter.com/iamjonsantiago/status/1247877412773298176 ("400+ years of enslavement, disenfranchisement, and imprisonment for poor people of color has created health inequity. Now you want me to save the ventilator for the "less sick"? No, sir. That's the definition of structural racism & we ain't about that"); *Kennedy & Santiago: Ventilator Guidelines Reinforce Racial Inequities* (Apr. 10, 2020), available at https://kennedy.house.gov/newsroom/press-releases/kennedy-and-santiago-ventilator-guidelines-reinforce-racial-inequities.

[15] *MBLLC Calls for A Pause in Crisis Standards of Care Guidelines* (Apr. 9, 2020), available at https://www.mablacklatinocaucus.com/our-work/mbllc-calls-for-a-pause-in-crises-standards-of-care-guidelines.

[16] *Rep. Pressley Calls on Governor Baker to Rescind Crisis of Care Standards that Disproportionately Harm Communities of Color & Disability Community* (Apr. 13, 2020), available at https://pressley.house.gov/media/press-releases/rep-pressley-calls-governor-baker-rescind-crisis-care-standards (letter closed with "ethically and morally there is a strong case to

of the Boston City Council convened a special hearing on April 22, 2020 to address the inequities and discrimination in the Crisis Standards of Care. Finally, the Massachusetts Coalition for Health Equity submitted an open letter to the administration signed by over 250 progressive physicians and medical students objecting to the CSC.[17] These intersectional concerns from a broad group resulted in overwhelming pressure to revise the CSC and presented a range of intersectional perspectives that clarified the potential discriminatory impact of the CSC.

The revised CSC released on April 20, 2020 did not fully resolve concerns over discrimination and spurred another round of advocacy.[18] However, as the rate of hospitalizations gradually plateaued and began to decrease in Massachusetts, it was clear that there was not an immediate need to invoke the CSC. Therefore, the coalition determined to continue to negotiate with state officials in order to address the remaining discriminatory elements of the revised CSC. At a meeting with the administration on July 9, 2020, a broad spectrum of intersectional advocates – including doctors, family members, attorneys representing disability, racial justice, and older adults organizations – discussed the discriminatory impact of the revised CSC. The coalition followed-up with a redlined version of the CSC for consideration by senior state officials.

### c. California

California adopted the broadest, intersectional approach from the outset. Disability Rights California (DRC) wrote to Governor Newsom with twenty-five steps "to protect Californians with disabilities" but expressly emphasized that "protecting everyone in this crisis is the best public policy."[19] Similarly, DREDF submitted a letter that expressly called for the recognition that people with disabilities live at multiple intersections of society and that discrimination can be compounded against those individuals in health care and other vulnerable settings during this pandemic.[20]

California released its first CSC document relatively late in its pandemic response, on April 20, 2020.[21] When it was released, the disproportionate negative impacts of the

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be made that it is in fact *because of* these factors, not in spite of them, that we must prioritize the health, safety and wellbeing of our most vulnerable above all else").

[17] *Open Letter to Crisis Standards of Care Advisory Committee*, available at https://www.slu.edu/medicine/diversity/open-letter.pdf.

[18] *Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic* (revised Apr. 20, 2020), available at https://www.mass.gov/info-details/covid-19-public-health-guidance-and-directives (still included age tie breakers and 5-year prognosis).

[19] DRC Mar. 16, 2020 letter to Governor Newsom, available at https://www.disabilityrightsca.org/post/drc-letter-to-governor-newsom-responding-to-coronavirus-covid-19 (describing specific interventions for public benefits, housing, education, criminal justice, and others).

[20] DREDF Mar. 20, 2020 letter to Governor Newsom, available at https://dredf.org/wp-content/uploads/2020/03/DREDF-COVID-19-Letter-to-Gov-Newsom.pdf.

[21] *California Authorities Issue a Wide Range of Rules and Guidance on COVID-19*, ROPES & GRAY (Apr. 28, 2020), available at

pandemic were measurable and well-known. In response to the State's newly revised CSC, DREDF formed an impressive coalition, with representatives from leading disability, racial justice, older adult, progressive, and poverty organizations, to request an effective overhaul of the new CSC. The coalition challenged the triage prioritization that measured life expectancy, a non-modified SOFA score and comorbidities, and demanded explicit commitments to non-discrimination and clear guidance to prevent implicit bias and all forms of discrimination.[22] The letter was signed by over 60 organizations representing historically disenfranchised, economically disadvantaged, and segregated communities including: gender groups, high weight individuals, older persons, individuals with disabilities, racial and ethnic advocacy groups, LGBTQ persons, chronic illness advocacy groups, civil rights advocacy organizations, and children and families.[23]

The State withdrew the CSC four days after release and spent the following month negotiating revisions to the standards, with substantial community input.[24] The revised CSC guidelines, released in June 2020, are widely-accepted and commended for disability accommodation and commitment to intersectional anti-discrimination policy.

## III. Lessons Learned and Best Practices in Developing an Advocacy Strategy Against Discriminatory Crisis Standards of Care

There are several lessons that should guide future challenges to the discriminatory denial of life-saving treatment, incorporated in state and hospital CSC. First, as the pandemic progressed, strategies to combat discrimination in CSC evolved and became more intersectional. Second, as intersectional coalitions were organized, they provided more powerful support for demands to completely revise CSC, rather than simply remove blatantly discriminatory provisions or modestly modify specific language. The strength of these coalitions in a negotiation process afforded the groups far more control over the outcomes, as opposed to delegating the process to discussions between state officials and OCR staff. Third, the broader the coalition, the more perspectives were presented, which resulted in more inclusive and better outcomes for all patients impacted by the CSC. And these discussions shifted the conversation from more narrow claims of discrimination to broad demands for health equity related to poverty, race, and disability in all aspects of crisis care. These issues are complex, impact millions and will not and cannot be resolved for a single population. It is short-sighted and ineffective to focus advocacy related to the pandemic solely through a disability lens. Instead, P&As should strive to develop credible and trusted partnerships with racial justice, aging adult, prisoner and other social justice organizations.

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https://www.ropesgray.com/en/newsroom/alerts/2020/04/California-Authorities-Issue-a-Wide-Range-of-Rules-and-Guidance-on-COVID-19-Update-2.

[22] Apr. 22, 2020 Large California Coalition letter, available at https://dredf.org/letter-opposing-californias-health-care-rationing-guidelines/.

[23] *Id.*

[24] *California SARS CoV-2 Pandemic Crisis Care Guidelines* (June 2020), available at https://www.cdph.ca.gov/Programs/CID/DCDC/CDPH%20Document%20Library/COVID-19/California%20SARS-CoV-2%20Crisis%20Care%20Guidelines%20-June%208%202020.pdf.

## IV. Strategies to Expand Intersectional Advocacy

P&As regularly participate in coalitions and collaborations to advance their policy, legislative, and administrative priorities. But these partnerships often are primarily comprised of disability organizations. The pandemic has offered a unique opportunity for – if not demanded – the creation of a broader and inclusive civil rights and health equity coalition that reflects the disparate impact of COVID-19 on communities of color, ethnic populations, immigrants, older adults, incarcerated or institutionalized persons, and low income citizens. P&As should consider a number of strategies to expand these partnerships beyond the usual disability organizations, including:

1. Think expansively about collaborating with a wide range of racial justice, community, family, worker, professional, political, academic, and advocacy organizations, including both familiar partners and new organizations or groups that include representatives of those communities most impacted by COVID-19. It is far less effective to narrowly focus on the issues and remedies relevant only to people with disabilities than it is to vision a response to the pandemic that is inclusive and intersectional. Silos in advocacy are just as misguided as they are in human service delivery models.

2. Collect and analyze data on the disparate impact of the pandemic. Identify the communities most affected by COVID-19, and develop a list of relevant organizations or stakeholders representative of these communities.

3. Collect and summarize professional research, local studies and data, and other relevant information concerning both the disparate impact of COVID-19 on these affected communities and the lack of an equitable response by public and private entities to the pandemic.

4. Draft a compelling analysis of what is at stake and why it is important to partner with all impacted communities.

5. Personally contact existing partners, like legal services, disability, and other advocacy organizations, to engage them in the importance of an intersectional response to the pandemic and to identify new potential partners.

6. Reach out and cultivate relationships with these new entities, including “cold calls” to stakeholders and organizations from identified communities that are not traditionally part of P&A or disability coalitions.

7. Conduct a targeted outreach effort to professional and academic research entities which can provide specialized expertise in addressing discriminatory aspects of pandemic responses.

7. Given the unique characteristics of the pandemic, develop a targeted outreach effort to medical and other health care workers to solicit their expertise and address their concerns with the impact of COVID-19 on their patients.

8. Build upon or organize a new coalition of organizations, representatives, professionals, and stakeholders from these identified communities with a mission to address specific policies or actions necessary to respond to COVID-19, like the rationing of life-saving medical treatment in Crisis Standards of Care, as well as the broader effects of health inequities.

9. Engage with political and other leaders of the impacted communities to enlist their voices in support of the coalition's priorities and activities.

10. Organize meetings, provide leadership, analyze data, develop policy responses, draft letters and reports, and offer communication and technology support to the coalition. Regularly disseminate information about COVID-19 responses by federal agencies, other states, and by local governments, such as the Evaluation Framework prepared by CPR and other national partners.[25]

While this intersectional coalition initially may focus on COVID-19 issues, including the broader impact of the pandemic on educational, legal, economic, transportation, and community development policies, it can provide the foundation for ongoing advocacy to address health inequities and discriminatory policies in many other domains. As issues continue to develop during the COVID-19 pandemic and beyond, beginning with more intersectional coalitions will strengthen advocacy and increase pressure on healthcare decision makers, and potentially result in greater success in dismantling discriminatory structures and policies.

## V. Conclusion

Over the course of this pandemic, advocacy against discriminatory CSC has evolved from narrow-focused, express discrimination to include intersectional broad coalition-based advocacy against implicit bias, discriminatory impact, and health inequities. P&As should assess CSC for both explicit and implicit discrimination, and their impact on all populations, including persons with disabilities, older adults, people of color, incarcerated persons, immigrants, and other disenfranchised groups. Since disability is inherently intersectional, P&As should engage broad coalitions representing these popultions and employ a variety of strategies, such as negotiation with government officials, complaints filed with OCR, media and legislative advocacy, and direct action to challenge discriminatory CSC. Once these coalitions are established, they can inform advocacy on other issues outside of health that arise during the pandemic and beyond.

[25] *See* n. 4, *supra.*