KENTUCKY P&A PROTECTION & ADVOCACY

Protecting and Promoting the Rights of Kentuckians with Disabilities

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VIA EMAIL: Eric.Friedlander@ky.gov

Eric Friedlander
Secretary
Cabinet for Health and Family Services
275 E. Main Street, 5C-A
Frankfort, Kentucky 40621

RE: Continued Discussion of Non-Discrimination and Health Care

Secretary Friedlander,

Thank you for providing Kentucky Protection & Advocacy's (P&A's) Medical Rationing Group on July 7, 2020 with the Revised Crisis Standards of Care (CSOC) and Strategies for Scarce Resource Situations (SSRS) in response to our April 20, 2020 letter. In April, the administration had succeeded in flattening the curve. However, recent data suggest that Kentucky is again on an upswing. This makes the remaining issues we raised all the more pertinent and immediate.

Fortunately, the passage of time has also provided guidance in the form of additional settlements/resolutions between the Office of Civil Rights (OCR) and Tennessee and Connecticut that informs us of language OCR considers necessary for the protection of patients with disabilities. This includes a focus on short-term survivability with treatment, reasonable accommodations and designated supporters for persons with disabilities, prohibitions against reallocation of a patient's personal ventilator, and clear guidance that individuals cannot be denied medical treatment based solely on a diagnosed disability or because they require more time or resources to recover due disability. Other states have made changes to their CSOC in response to and in consultation with groups such as ours, demonstrating that these revisions are both feasible and necessary to ensure patients are protected from discrimination.

First, we appreciate the many changes made to both the CSOC and the SSRS. Specifically and appropriately, they clarify that treatment decisions are to be determined by an individualized assessment of objective medical evidence; remove criteria based on long-term survivability, resource intensity and duration of need; and require modifications and accommodations for all assessments, including the Sequential Organ Failure Assessment (SOFA). These changes are in line with federal anti-discrimination law and with what we requested. However, the guidance on Mechanical

Ventilation/External Oxygenation in the SSRS continues to list specific diagnoses on page 11, 2b and continues to use "Duration of need" which undercuts the accommodation language in the CSOC. One of the problems of listing diagnoses is that it may lead to an assumption that the diagnoses is determinative of prognosis without performing any analysis of the current and best available objective medical evidence and the individual's ability to respond to treatment. California's SSRS, part of one of the most comprehensive crisis standards of care, is identical to Kentucky's except it does not include either the Mechanical Ventilation/External Oxygenation or the Renal Replacement Therapy sections.[1] The disability community considers the "California SARS-CoV-2 Pandemic Crisis Care Guidelines" as the gold standard; accordingly we attach it for your review.

Finally, Kentucky continues to rely on predictions of life expectancy and one to two year prognosis in prioritizing patients for life-saving care, despite recent actions by OCR and the emergence of other state models focused on short-term survivability. Numerous studies have shown that attempts to predict life expectancy and prognosis are often inaccurate and unreliable, even under normal standards of care.[2] In the triage context, these predictions can be even more fraught, relying on imperfect information, mistaken stereotypes and assumptions about diagnosis and quality of life, and other forms of unconscious bias.[3]

As the New England Journal of Medicine recently noted:

> In effect, [Crisis Standards of Care] that deprioritize people with coexisting conditions or with a higher likelihood of death within 5 years penalize people for having conditions rooted in historical and current inequities and sustained by identity-blind policies. In the United States, black, poor, disabled, and other

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[1] http://healthimpact.org/wp-content/uploads/2020/06/California-SARS-CoV-2-Crisis-Care-Guidelines-June-8-2020_rs.pdf. The SSRS section begins at page 31.

[2] *See*, Life Expectancy Estimates: A Survey of Research on Prognosis, available at https://www.centerforpublicrep.org/wp-content/uploads/Life-Expectancy-Studies-Crisis-Std-of-Care-for-Covid-19-6.30.20.pdf.

[3] *See, e.g.*, Colin A. Zestcott, et al. *Examining the presence, consequences, and reduction of implicit bias in health care: A narrative review*, 19 Group Processes & Intergroup Relations 528, 529 (2016), (citing multiple studies showing that implicit bias and stereotypes impact judgment and behavior of health care providers when interacting with patients from minority populations); National Council on Disability, *Medical Futility and Disability Bias*, Bioethics & Disability Series 1, 29 (2019), ("Several studies have demonstrated that health care providers' opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people."); Lynne D. Richardson, et al., *Racial and Ethnic Disparities in the Clinical Practice of Emergency Medicine*, 10 Acad. Emergency Med. 1184, 1184-85(2003), ("Situations, such as the emergency department (ED), that are characterized by time pressure, incomplete information, and high demands on attention and cognitive resources increase the likelihood that stereotypes and bias will affect diagnostic and treatment decisions."); 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.")

> disadvantaged people have shorter life expectancies than white and able-bodied Americans. If maximizing life-years is the prime directive, their lives will be consistently deprioritized as compared with already-advantaged groups.[4]

By negotiating a resolution that limits use of prognosis criteria to short term survivability with treatment as was done in Tennessee,[5] OCR has made clear that State crisis standards should strive to eliminate the risk of inaccurate and discriminatory criteria, especially among people with disabilities and communities of color. Making changes to or totally deleting those sections of the SSRS are necessary to protect patients with disabilities facing those situations.

We believe the following further revisions are necessary to fully protect patients with disabilities:

1. Neither the CSOC nor SSRS prohibits the reallocation of an individual's personal ventilator. Individuals who are dependent on a ventilator should not fear that if they go to a hospital that they might be stripped of their personal ventilator so it can be reallocated to another patient. The lack of any explicit prohibition on such an action is tantamount to permission and creates a chilling effect on vent-dependent individuals who need hospital-level care. We request that both the CSOC and SSRS contain an explicit prohibition against such a reallocation.
2. Any consideration of life expectancy or prognosis should be limited to short term mortality and survivability with treatment. By aligning Kentucky's crisis standards with established medical research, the recent OCR resolution in Tennessee, and emerging best practices in other states, this Administration can mitigate the potential for explicit and implicit discrimination against patients more likely to have underlying, chronic conditions, or overall shorter life expectancies, including people with disabilities, older adults, and communities of color. To the extent any predictions of short-term survival beyond the acute episode are required, triage clinicians should be directed to make conservative judgments, to not assume the mere existence of an underlying disability or medical condition negatively impacts short term survival, and to not assign points when a patient's prognosis is uncertain.
3. Neither document provides a general statement of anti-discrimination reminding hospitals of the federal mandate to provide reasonable accommodations in all aspects of patient care. While the Revised CSOC and SSRS for the most part provide excellent language regarding life-saving treatment and crisis situations,

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[4] *Inequity in Crisis Standards of Care* Emily Cleveland Manchanda, M.D., M.P.H., Cheri Couillard, M.A., and Karthik Sivashanker, M.D., M.P.H., N. Engl. J. Med., May 13, 2020. https://www.nejm.org/doi/full/10.1056/NEJMp2011359.

[5] As a result of the OCR negotiation process, Tennessee has eliminated longer-term survivability as a consideration in the allocation of scare resources. Instead, OCR approved Tennessee's revised standards that allows medical personnel to consider only the "imminence of mortality," or survivability with treatment, when making triage assessments which would deny life-saving treatment. https://www.hhs.gov/about/news/2020/06/26/ocr-resolves-complaint-tennessee-after-it-revises-its-triage-plans-protect-against-disability.html

there should also be a general statement of anti-discrimination. The aforementioned "Tennessee Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency as Declared by the Governor of Tennessee" contains a section entitled, "Statement of the Application of Civil Rights Laws during an Emergency," which directly quotes general anti-discrimination language as written in the March 28, 2020 OCR Bulletin, "Civil Rights, HIPAA, and the Coronavirus Disease."[6] Since Kentucky's CSOC addresses much more than life-saving treatment, we maintain that a general statement of anti-discrimination law should be included in the CSOC. One suggestion would be to place that statement in the Guiding Principles which begin at page 5 of the CSOC with reference to it in the section entitled "Hospital and ICU Exclusions" on page 14.

4. In our April 20 letter, we requested language regarding a "Visitation" Policy, which should more appropriately be called a "Designated Support Person" Policy. That is the term used in the Connecticut Executive Order, which arose from the resolution of another OCR complaint.[7] The point of our request is to differentiate between a visitor and a support person. A visitor is someone who is present to spend time with or provide emotional comfort to the patient. In contrast, a support person provides services necessary to ensure the individual has equal access to medical treatment, effective communication, and the ability to make informed decisions and provide consent. A visitor may be limited or prohibited under hospital policy; a support person is a reasonable accommodation whose access to the patient is necessary to their equal access to care.
5. Neither of the revised documents addresses an appeals process as we requested. Massachusetts's Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic contains an entire section on this issue.[8]
6. Disability awareness training is also not included. Both California[9] and Pennsylvania[10] require triage teams to receive such training. The California training must include avoiding implicit bias, respecting disability rights, and diminishing the impact of social inequities on health outcomes at page 11.

Again, we appreciate the progress demonstrated by the revisions to date to both documents. As COVID-19 cases in the state increase and we face a second wave of infection, we hope that you will again step forward on behalf of individuals with disabilities and work to ensure their continued safety and equal treatment and access to care through further revisions to both of these documents.

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[6] See Footnote 5, page 14.
[7] https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html
[8] https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download
[9] See Footnote #1.
[10] https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID-19%20Interim%20Crisis%20Standards%20of%20Care.pdf

We would welcome the opportunity to further discuss these proposed changes with you. Please feel free to contact either me should you have any questions or would like to schedule a time to meet.

Please let us hear from you by July 22, 2020.

Respectfully,

Jeff Edwards
Director

Arthur Campbell Jr.
A Disabled Activist
And A Civil Rights Worker

Tina Jackson
PADD Board Member
Disabled Self-Advocate

Epilepsy Foundation of Kentuckiana

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Cc: Wesley W. Duke, General Counsel

Attachment: California SARS-CoV-2 Pandemic Crisis Care Guidelines