



Protecting and Promoting the Rights of Kentuckians with Disabilities

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VIA EMAIL: Eric.Friedlander@ky.gov

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

RE: Non-Discriminatory Allocation of Medical Resources

Secretary Friedlander,

Thank you for sharing with Protection and Advocacy's (P&A's) Medical Rationing Group the Crisis Standards of Care (CSOC), Strategies for Scarce Resource Situations (SSRS), and Dr. Steven Stack's letter dated March 30, 2020 as the guidance issued for healthcare providers to follow in the current coronavirus pandemic. As I mentioned when we spoke on April 15, 2020, P&A's Group had reviewed the CSOC and were concerned that it left individuals with disabilities vulnerable to discrimination. You offered to work with us to address our concerns. We have since reviewed all three documents and now offer the following recommended revisions to the CSOC and SSRS.

Governor Beshear has regularly emphasized the need for inclusivity in his daily briefings. He has demonstrated his commitment to inclusion through the services of ASL Interpreters and by featuring videos of individuals with disabilities during his briefings, including one from a member of the P&A Protection and Advocacy for Individuals with Developmental Disabilities (PADD) Board. Similarly, Dr. Stack's letter identifies his commitment to inclusion by identifying the following elements as essential in guiding ethical principles for decision-making: respect for human dignity, communication, reciprocity, duty of care, and consistency and fairness.

A group of physicians, nurses, public health experts, and bioethicists began creating the CSOC in 2012. It appears that no group member was a person with a disability or representative of the disability community. The CSOC does not mention the Americans with Disabilities Act or Section 504 of the Rehabilitation Act. Both laws must inform any discussion of the treatment of people with disabilities, particularly when allocating scarce medical resources in a public health emergency such as a pandemic. Individuals with disabilities face the most severe consequences of such allocations; their voice

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should have been heard and acknowledged during the process of the CSOC's creation. We are glad that they are being heard now.

We believe the following recommended revisions to the CSOC and the SSRS will ensure the Commonwealth's guidance is more consistent with the Governor's and Dr. Stack's commitment to ensuring Kentuckians with disabilities receive equitable treatment during the pandemic.

CRISIS STANDARDS OF CARE (CSOC)

Of specific concern is page 35 of the CSOC, which address "Hospital and ICU Exclusions." It offers healthcare providers three criteria for determining whom they should exclude from potentially life-saving care. We wrote to you on April 7, 2020, noting that the Americans with Disability Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act apply to healthcare providers and their decisions. As written, all three criteria permit the discriminatory treatment of individuals with disabilities in contravention of these federal laws. We respectfully request consideration of the following changes to the CSOC. We have underlined and bolded proposed additional language and struck-through language we believe needs to be removed.

HOSPITAL AND ICU EXCLUSIONS

"Given the charge to do the best for the most, saving as many lives as possible with a marked scarcity of resources, there are ~~certain medical conditions or~~ **may be** situations where maximally aggressive care will not be able to ~~cannot~~ be provided to every individual. **However, federal law prohibits discrimination in the delivery of medical services, including during community-wide public health emergencies and when resources are limited. All treatment decisions must be derived from an individualized assessment based on objective medical evidence. No patient should be disqualified from life-saving treatment solely because of underlying disabilities, diagnosis, functional impairment, Activities of Daily Living needs, or co-morbid conditions.** These individuals would include:"

RATIONALE

The Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA) are anti-discrimination laws that prohibit discriminatory practices in the provision of medical services. On March 28, 2020, the U.S. Department of Health and Human Services' (HHS') Office of Civil Rights (OCR) issued a bulletin, which affirmatively states that Sections 504 and 1557, like other civil rights statutes including the ADA, remain in effect during the COVID-19 pandemic.¹ OCR Director Roger Severino noted that "HHS is committed to leaving no one behind during

¹ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

an emergency” and that persons with disabilities “should not be put at the end of the line for health care during emergencies.” This affirmative anti-discrimination statement within Kentucky’s guidance is to remind providers of federal requirements not to put individuals with disabilities at the end of the line for life-saving care during this or any future public health crisis.

CRITERIA 1

“~~Those who are~~ **Comfort care will be provided where the individual is** too ill to likely survive the acute illness **based on an individualized assessment of the patient. All assessments must be based on the best available objective medical evidence and administered with appropriate accommodations and modifications.** (as evidenced by the Sequential Organ Failure Assessment (SOFA) score). See attachment 7

RATIONALE

The first criteria excludes those too ill to likely survive the acute illness. While on its face this seems like a reasonable measure, the state’s reliance on the Sepsis-related Organ Failure Assessment (SOFA) score as a primary, albeit not exclusive, measure may result in unintended discrimination against individuals with disabilities. The state must include provisions to ensure that reasonable modifications are made for those whose underlying impairments result in a SOFA score that penalizes them for their baseline level of impairment prior to the acute care episode.

For example, the SOFA incorporates the Glasgow Coma Scale, which is a tool for measuring acute brain injury severity. If administered without accommodations, a patient with a pre-existing speech disability who cannot articulate intelligible words cannot achieve a full score on the Glasgow Coma Scale. In turn, the failure to achieve a full score on the Glasgow Coma Scale artificially inflates the SOFA score. The higher the SOFA score, the lower the estimated likelihood of survival. Thus, a nonverbal patient’s score would identify him as less likely to survive the acute illness than an identical, but verbal, peer. Patients with pre-existing motor impairments are similarly disadvantaged by this measure.

Policy must clearly indicate that any measure of survivability should be objective and should be modified to hold patients harmless for underlying disabilities not relevant to short-term survival in the context of COVID-19 or any future community-wide public health emergencies.

CRITERIA 2

“~~Those whose underlying medical issues make their one-year mortality probability so high that it is not reasonable to allocate critical care resources to them; for example, end-stage ALS, metastatic carcinoma refractory to treatment and end-stage organ failure”~~

RATIONALE

There is a spectrum of disabilities with a myriad of biomedical causes that are too widely varied and too poorly understood to be reliably used as evidence-based predictors of life expectancy or quality of life. In 2015, the New York Taskforce on Life and the Law published “Ventilator Allocation Guidelines,” which note, “Triage decision-makers should not be influenced by subjective determinations of long-term survival, which may include biased personal values or quality of life opinions.”² Intermediate or long-term prognosis should not be factors in determining priority for lifesaving treatment. Attempts to predict long-term prognosis, especially for persons with disabilities, can lead to erroneous, inconsistent, and subjective decision-making in violation of federal anti-discrimination laws.³ Triage decisions should be governed solely by individualized assessments of the patient’s potential for survivability to discharge. Accordingly, we recommend deleting this criteria.

CRITERIA 3

~~“Those who require a larger than normal amount of resources, which makes it not feasible to accommodate their hospitalization in a prolonged mass-casualty situation.”~~

RATIONALE

Our fellow citizens with disabilities are at all levels of functionality; however, historically they have been generalized as being “burdens on society” and that view perpetuates today. Concerns are frequently raised over an individual’s use of Medicaid dollars or the need for additional medical services or equipment to accommodate needs. Individuals should not be forced to compromise quality of life supports or relinquish medically necessary care and accommodations for fear they will be perceived as someone who “require[s] a larger than normal amount of resources” that would in turn disqualify them from life-saving care. Further, additional resources may in many instances be mandated as a reasonable accommodation under the ADA and Section 504 for a person with a disability to have equal opportunity to benefit from the treatment. Triage decisions should not be based on subjective opinions or the need for reasonable modifications, but instead be governed solely by individualized assessments of the patient’s potential for survivability to discharge. Accordingly, we recommend deleting this criteria.

LOCAL CONTROL

~~All of the medical states or long-term conditions excluded from hospital care in this guidance meet at least one of the above criteria. In these cases, comfort care will be the~~

² https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf

³ “I would probably say that your general population of people with disabilities are the most resilient people that you will ever meet.” Natasha Miller, mother of Isaac, a 14-year-old young man with Nager Syndrome, as quoted in a recent news article. Available at: http://www.floydct.com/covid-19/organizations-ask-the-state-to-protect-those-with-disabilities/article_1d63149c-7a86-11ea-b38f-2b2eadd46783.html

~~priority. There could be several possible exclusion groups but these decisions will be decided locally. Those with known DNR status do not necessarily meet any of the three criteria above. Those with known severe dementia have a relatively high mortality and may require more care resources than may be available, but there is wide variance in the severity of the disease between individuals. The same could be said of those over 85 years old. Certainly as a group, this older population is less likely to survive an acute illness, has a relatively high one-year mortality rate and may require more resources than will be available for both acute care as well as convalescence. Again, however, there may be a wide variation in individual functional status. For all the reasons listed above, these groups of individuals were not placed in the exclusion list and would be decided on by local facilities.~~

RATIONALE

The underlying purpose of establishing these state guidelines is to provide a uniform system of response to a public health emergency. While local decisions must conform to anti-discrimination laws, the abdication of decision-making to local districts during a crisis will result in the unpredictable and inconsistent provision of medical care for individuals with disabilities. The example provided in the above paragraph clearly demonstrates the need for uniform guidance. As a group, individuals over 85 are noted to meet all three of the current criteria and could be excluded from treatment, yet two⁴ 107 year-old individuals have recovered from COVID-19. While this group is not placed on the exclusion list, allowing local facilities to create their own local exclusion groups would mean that an elderly adult might get treatment in one county, but that same person would be excluded from treatment in a neighboring county. For this reason, we recommend deleting this criteria.

ATTACHMENT 7: SOFA SCORE

It is important to remember that SOFA is a single criteria, and other patient factors (e.g., underlying diseases and current response to treatment) should be taken into account when making triage decisions. (Add information about its problems, plus adjusting scores or not scoring) **Triage teams and any healthcare professional using the SOFA must avoid penalizing individuals with chronic but stable underlying conditions, including individuals with disabilities, when calculating SOFA scores. Baseline levels of impairment, prior to the acute care episode, should not increase SOFA scores unless objective medical evidence, interpreted by a medical professional with expertise necessary to exercise professional judgment under usual standards of care, demonstrates that those conditions directly impact an individual's short term survivability with treatment.** Disease-specific predictive factors may also need to be accounted for and included in the triage decision-making. Assuring that the triage team members are experienced critical care providers

⁴ <https://www.dailymail.co.uk/news/article-8216871/Turkish-woman-second-107-year-old-beat-coronavirus.html>

that have access to the relevant patient information, guidance, and are part of a defined, structured process for triage whenever possible is critical to making fair, accountable, transparent decisions about resource allocation.

RATIONALE

Two documents, the CSOC through Attachment 7 and the SSRS, provide guidance regarding the allocation of scarce resources, like ventilators, during community-wide public health emergencies. Both documents recommend using the SOFA as a primary assessments to be used to make allocation determinations. As noted above in the discussion of Criteria 1, individuals with underlying impairments may be penalized for their baseline level of impairment prior to the acute care episode in computing a SOFA score and federal anti-discrimination law requires reasonable modifications. “Plans must clearly indicate how instruments like the SOFA should be modified to hold patients harmless for underlying disabilities not documented to be relevant to short-term survival in the context of Covid-19.”⁵ Accordingly, the Group recommends adding the proposed language to the CSOC as well as modifying the SSRS. The proposed language notes the obligation to and method for modifying medical assessments to account for and accommodate underlying disabilities not relevant to the assessment of short-term survival.

STRATEGIES FOR SCARCE RESOURCE SITUATIONS (SSRS)

Beginning on page 10, SSRS provides a three-step process for re-assigning ventilators. Step One employs the SOFA scoring table; our concerns about this metric are noted above. Step Two then takes those SOFA scores and adds three additional criteria (duration of benefit/prognosis; duration of need; and response to mechanical ventilation). Criterion one, duration of benefit/prognosis, has two parts—the first looks at prognosis for “the specific disease”, i.e. COVID-19 and is, as we have previously noted, permissible. The second part looks at “underlying disease” which is, as also noted above, permissible only when based on an objective, individualized assessment completed with accommodations. Criterion two—duration of need—penalizes patients who require longer time on the ventilator, something which as noted above, may require reasonable accommodations under federal anti-discrimination laws. Criterion Three, response to mechanical ventilation, is also problematic, and is discussed below in Ventilator Trial Period Extensions. Finally, Step Three requires re-allocation of a ventilator where a patient in respiratory failure has a “significantly better chance of survival/benefit.” As noted above, decisions to refuse or reallocate resources should be based on individualized, objective criteria with accommodations that measure a patient’s prognosis for the acute care episode. We are concerned that “significantly

⁵ “When It Comes to Rationing, Disability Rights Law Prohibits More than Prejudice,” Ari Ne’eman, Published in: Covid-19, Disability, Hastings Bioethics Forum, Health and Health Care, April 10, 2020. Available at: <https://www.thehastingscenter.org/when-it-comes-to-rationing-disability-rights-law-prohibits-more-than-prejudice/>

better chance of benefit” is a subjective determination that opens the door to bias about quality of life decisions.

The SSRS applies the same reallocation decision-making process when there is a shortage of dialysis machines. We reiterate our concerns and recommendations for resource allocation decisions made in this context.

ADDITIONAL RECOMMENDATIONS

We are further concerned that the CSOC lacks any guidance regarding the need to comply with federal anti-discrimination laws. State policy should embed federal requirements into guidance regarding the withdrawal or removal of personal lifesaving equipment, extensions of ventilator trial periods, general accommodations, and hospital visitation policies. Policy should also set forth an appeals process as well as triage team training.

WITHDRAWAL OR REMOVAL OF PERSONAL LIFESAVING EQUIPMENT

“Individuals presenting for hospital level of care will not be subject to the automatic withdrawal, removal, or redeployment of personal lifesaving equipment, including ventilators, based on discriminatory assumptions about their intensity of need or likelihood of recovery.”

RATIONALE

Individuals who routinely use ventilators in the community may require acute hospital care during the pandemic. They should not face the possibility of discriminatory removal of those ventilators. We recommend adding the above language to the CSOC to clarify that individuals will not be subject to the withdrawal or removal of personal lifesaving equipment.

VENTILATOR TRIAL PERIOD EXTENSIONS

“Treating doctors and triage teams must provide reasonable accommodations to triage protocols for individuals with disabilities, including the extension of ventilator trial periods, when patients are expected to recover, but may require additional time to demonstrate effective progress because of their disability.”

RATIONALE

State policy should also clarify that certain triage criteria, such as limitations on how long patients may stay on a ventilator without demonstrated improvement, or using “long duration” to cause re-allocation of a ventilator as found in Step Two of the SSRS

(discussed above) may have a disproportionate, negative impact on individuals who are no less likely to recover, but may do so more slowly due to a pre-existing disability.

GENERAL ACCOMMODATIONS

“Hospitals must:

- a. Provide effective communication with individuals who are deaf, hard of hearing, blind, and visually impaired through the use of qualified interpreters, picture boards, and other means;
- b. Provide meaningful access to programs and information to individuals with limited English proficiency through the use of qualified interpreters and through other means;
- c. Make emergency messaging available in plain language and in languages prevalent in the affected area(s) and in multiple formats, such as audio, large print, and captioning, and ensuring that websites providing emergency-related information are accessible; and
- d. Address the needs of individuals with disabilities, including individuals with mobility impairments, individuals who use assistive devices or durable medical equipment, and individuals with immunosuppressed conditions including HIV/AIDS in emergency planning.”

RATIONALE

The CSOC should either reference the language in the OCR Guidance regarding reasonable accommodations or directly include it.

“VISITATION” POLICY

“Patients with disabilities who need assistance due to the specifics of their disability may have one designated support person with them. This could include specific needs due to altered mental status, intellectual or cognitive disability, communication barriers, or behavioral concerns. If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant, or disability service provider knowledgeable about the management of their care to physically or emotionally assist them during their hospitalization, this will be allowed with proper precautions taken to contain the spread of infection.”⁶

⁶ COVID-19 visitor policy of Rush University Medical Center, Illinois, available at <https://www.rush.edu/patients-visitors/covid-19-resources/rush-coronavirus-covid-19-patient-and-visitor-updates>.

RATIONALE

Many individuals with disabilities require the assistance of necessary adaptive equipment and/or caregivers. When this assistance is necessary to accommodate the individual's needs, the request to have a caretaker accompany the individual is a request for an accommodation and not a visitor. Some hospitals, however, have denied entry to caregivers as against their visitation policies. Inclusion of the suggested language will ensure that hospitals do not deny individuals with disabilities medically necessary and statutorily required accommodations. For this reason, we request adding the proposed language to the CSOC.

APPEALS PROCESS

Decisions using these guidelines will have significant consequences. For that reason, there should be an appeals process, transparent and capable of quickly occurring, to protect individuals' basic rights. The process should be explained to all patients and their representatives at admission and again if a triage decision results in a person being denied, losing access to, or removal of, a ventilator or other life-saving medical equipment, treatment, or care.

DISABILITY AWARENESS TRAINING

Triage Teams and other healthcare professionals should be required to undergo Disability Awareness Training to alert them to weaknesses in the SOFA scoring system as well as to recognize and eliminate possible biases. As noted by Director Severino, "Decisions cannot be made on the basis of stereotypes, assessments of qualities of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities."⁷

We are hopeful that you will consider these recommendations and that we can continue to work collaboratively. As you may be aware, at least nine other Protection and Advocacy organizations, along with other national disability rights organizations like The Arc of the United States, the Center for Public Representation, Autistic Self Advocacy Network, Disability Rights and Education Fund, and the Bazelon Center; state organizations; and individuals with disabilities and their family members have filed OCR complaints. Two of those complaints—in Alabama and Pennsylvania—have been resolved. We are pleased that Kentucky is willing to work in collaboration with our agencies to resolve our concerns.

It now appears that the Governor's swift action and the cooperation and sacrifice of the citizens of the Commonwealth have flattened the curve to the extent that the imminent threat of decision-making about scarce medical resources has been averted, at least for the first wave of the pandemic. However, experts are predicting a second wave, and we

⁷ See FN 1.

must ensure that Kentucky follows the law and that this vulnerable population can benefit from the inclusion embraced by this administration.

When they are complete, we ask that these revisions be incorporated into Kentucky's Crisis Standards of Care and Strategies for Scarce Resource Situations, and issued as an executive order—highlighted at the Governor's daily briefing—to maximize awareness of these changes and to ensure health care providers are aware of and follow the revised guidance. In addition, they should be publicly available, and in accessible formats.

We appreciate the Governor's ongoing dedication to inclusions and your willingness to work with us to ensure full inclusion in the administration's policies. Please let us hear from you by April 27, 2020.

Respectfully,



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The Council on Developmental Disabilities

Cc: Wesley W. Duke, General Counsel

