Disability Rights OHIO

We have the legal right of way

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Mr. McGlone and Ms. Hunt:

We are writing to follow up after our conversation earlier this week regarding the Ohio Hospital Association's "Guidelines for Allocation of Scarce Medical Resources." Again, we appreciate your time and your willingness to engage with us on these important issues.

Our previous letter outlined the primary concerns we have with the guidelines. At your request, below we explain ways the OHA should revise its guidelines to help ensure people with disabilities are not subjected to discrimination.

1. Exclusion criteria based on diagnosis or condition should be removed.

We have previously noted our concerns that the guidelines could unfairly penalize people with disabilities for pre-hospitalization conditions that are unrelated to their ability to respond to treatment or their short-term survivability.

We think the guidelines should not contain any exclusion criteria based solely on diagnosis or condition (see page 24 of the guidelines). Some of the criteria are particularly problematic, including, without limitation, denying care to a person with an "advanced and irreversible immune-compromised condition." Specific categories of exclusion are unnecessary, in our view, if hospitals properly conduct individualized assessments, based on the best available objective medical evidence, to determine a patient's ability to respond to treatment and short-term survivability.

Massachusetts' Crisis Standards of Care (see page 22, attached) avoids the use of categorical exclusion criteria. On page 18 of its guidelines, it explains: "The mere existence of certain underlying medical conditions (including without limitation a diagnosis of end stage renal disease, a diagnosis of congestive heart failure, or a diagnosis of dementia) should not be used in and of themselves to assign points without objective, medical evidence that such conditions are of a severity that would significantly limit near term life expectancy."

2. Further direction and clarification is needed for SOFA and Glasgow Coma scores so that people with disabilities are not unfairly penalized.

Regarding SOFA and Glasgow Coma scores, hospital guidelines in other states have included clarifying language to ensure people with disabilities are not unfairly penalized:

- Massachusetts' Crisis Standards of Care say (see pages 17-18): "Regarding the use of the SOFA score as a marker of prognosis for short-term survival, there are several objective scoring systems used to assess severity of critical illness and likelihood of survival, but each has limitations and all, including SOFA, should be applied and adjusted in the context of clinical judgment. For example, the Glasgow Coma Scale, a tool for measuring acute brain injury severity in the SOFA, adds points to the SOFA score when a patient cannot articulate intelligible words, even if this condition is due to a pre-existing speech disability or chronic ventilation. Baseline levels of impairment prior to the acute care episode should not increase SOFA scores for purposes of this protocol unless those conditions directly impact an individual's short-term survivability with treatment."

- Delaware Crisis Standards of Care say (see page 17, attached): "Baseline levels of impairment should not increase SOFA scores unless evidenced as interpreted by an expert medical professional demonstrating that those conditions directly impact an individual's short-term survivability." Furthermore, "[t]riage teams should avoid penalizing individuals with chronic but stable underlying conditions, including individuals with disabilities, when calculating SOFA scores."

We suggest adding similar language to provide direction to hospital clinical staff. Though you had said the guidelines must be read as a whole, and that non-discrimination principles should apply to these determinations, we are worried about how this will work in practice. Clarifying language would reinforce these principles and explain the ways in which people with disabilities could be penalized.

3. <u>Ambiguities in the exclusion criteria should be eliminated.</u>

There are also ambiguities and a lack of specificity in other parts of the exclusion criteria on page 24, as we mentioned in our previous letter. A reminder about the obligation for individualized assessments, based on the best available objective medical evidence, should be added to the statement "[i]dentify patients who are unlikely to benefit from critical care intervention."

The guidelines also say "[p]atients, in general, are excluded from consideration for critical care" when a patient has a "low probability of survival despite intensive care." This should be clarified that it refers to short-term survivability (i.e., six months), as long-term predictions are notoriously difficult to predict accurately. Another concern is excluding a patient from critical care intervention when he or she "requires resources that cannot be provided." This provision should be removed, in our view, unless language is added that clarifies hospital systems should work with other hospital systems in Ohio and other states to explore whether resources may be available for the patient.

And finally, the guidelines state that a patient can be excluded from critical care intervention when the patient's "underlying illness has a poor prognosis with a high likelihood of death." We are concerned that there is no time limitation here, so reference to short-term survivability (i.e., six months) should be added.

4. <u>Provisions about reallocation of ventilators should clarify that no person with a disability should ever have their ventilator taken away, and that allocation of ventilators within a hospital system should respect non-discrimination principles.</u>

We assume that provisions in the guidelines about reallocation of ventilators refer to the hospital system's ventilators, not one's own personal ventilator. This should be clarified. Disability rights advocates in New York have observed that "[c]hronic ventilator users may not seek necessary acute care because of fear that they will be assessed ineligible for continued ventilator use and have their personal ventilators reallocated to 'healthier' individuals."

And to the extent that a shortage of ventilators in a hospital system becomes reality, and no alternative resources are otherwise available, allocation of this equipment should be based on objective, non-discriminatory standards.

5. <u>The guidelines should contain provisions about the obligation to reasonably accommodate the needs of people with disabilities.</u>

The Americans with Disabilities Act requires that hospitals reasonably accommodate the needs of people with disabilities to ensure equal access to their services, care, and equipment. As we noted previously, a person may have limitations in expressive or receptive communications (like a person with autism) and may need assistive technology or a family or caregiver, or may have different ways of communicating (like someone who is deaf and communicates through ASL). Accommodating these needs and ensuring effective communication is one important way to avoid discrimination against people with disabilities.

The guidelines should mention these obligations generally and also specifically in the context of the strict requirement for reassessment of one's SOFA score after 48 hours of "trial of therapy" (see flowchart on page 25). Some people with disabilities may need more time to recover. For example, Delaware's Crisis Standards of Care (page 17) provide that "[r]easonable accommodations to triage protocols for individuals with disabilities should be considered, including the extension of ventilator trial periods to allow additional time to demonstrate effective progress because of their disability."

6. <u>The guidelines should contain an appeals process to ensure transparency and accountability.</u>

By way of example, Pennsylvania's Crisis Standards of Act (beginning on page 47, attached) contains important language about appeals and oversight:

> Even the proper execution of crisis standards of care and triage principals may cause discomfort or even anger from families or caregivers of patients. The improper execution of these standards would constitute a serious breach of conduct by the providers. In either regard, patients, family members, or caregivers who have concerns should be referred to the facility's Patient Rights and Responsibilities procedures for concerns or complaints. … Unresolved complaints can be filed with the department by [contacting the hospital by phone].

People with disabilities, families, and caregivers should also be directed to contact Disability Rights Ohio for advice and advocacy.

Conclusion

Thank you for carefully considering our concerns and proposed revisions. Please note that although we cite to several states' guidelines as examples, we do not necessarily endorse those states' entire guidelines, as other sections may illegally discriminate against people with disabilities.

Regardless, we hope to continue our dialogue and appreciate your time and attention. Please let us know if you have any questions about this letter or previous correspondence.

Respectfully,

/s/ Kevin Truitt
Kevin Truitt
Attorney at law