Disability Rights OHIO

We have the legal right of way

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Mr. McGlone and Ms. Hunt:

As promised, below we elaborate on the concerns with the Ohio Hospital Association's "Guidelines for Allocation of Scare Medical Resources" we noted in our previous letter.

We appreciate your willingness to engage with us on these important issues, and we are looking forward to our conversation on Monday morning. Even if the OHA does not have the authority to require hospitals to implement specific plans, its leadership and influence are crucial in ensuring the rights of people with disabilities in Ohio.

1. <u>The guidelines' Crisis Standard of Care exclusion criteria may impermissibly and illegally discriminate against people with disabilities.</u>

There are several problems with the exclusion criteria (page 24 of the guidelines), but fortunately solutions should not be difficult to incorporate into revised guidelines.

First, people are excluded from admission or transfer for critical care treatment in a number of circumstances, including those where a person has a Sequential Organ Failure Assessment (SOFA) score equal or greater than 11. The SOFA score relies on pre-existing conditions or diagnoses, which means there is a risk that people with disabilities may be unfairly penalized for conditions or disabilities that are unrelated to their ability to respond to acute care treatment or to short-term survivability. These individuals may start at a higher SOFA score as their baseline. And a higher score represents a greater chance of being denied care or equipment on the basis of their disability, which is discriminatory under federal law, including the Americans with Disabilities Act ("ADA").

The guidelines also make reference to the Glasgow Coma Score, which is described in Appendix B. A lower score here penalizes people with disabilities, again for pre-existing factors which may be unrelated to their ability to benefit from acute care treatment or to short-term survivability. An adult or child with a vision impairment may be unable to open their eyes. A person with a developmental disability, like autism, may not be able to communicate orally or may make incomprehensible sounds or use inappropriate words. A person with physical disabilities may show no motor response. These disabilities should not be a basis for disqualifying people from care or treatment or equipment.

The ADA requires reasonable modifications to hospitals' policies to avoid discrimination on the basis of disability. We appreciate that the guidelines say that, for SOFA and Glasgow Coma scores, "clinical staff should check for underlying disability conditions that are not consistent with disease progression before

patients are scored" (pages 37-38). But there is no explanation on how this should work in practice. Further direction and clarification are needed to ensure people with disabilities are not unfairly penalized and that underlying disabilities or other conditions do not inappropriately distort a determination of whether one's ability to benefit from treatment or an assessment of short-term survivability.

The exclusion criteria also mention specific conditions or diagnoses, like "[a]dvanced and irreversible immune-compromised condition," and "known or previously documented end-stage organ failure meeting the following criteria: (1) heart (NYHA class III or IV heart failure; (2) lungs (end stage COPD, cystic fibrosis, pulmonary fibrosis, or end state pulmonary HPT); (3) liver (Child-Pugh score equal or great than 7)." Categorical exclusions based solely on diagnosis or condition are problematic, as they deviate from the standard of requiring individualized assessments based on the best available objective medical evidence.

There are also ambiguities and a lack of specificity in other parts of the exclusion criteria. For example, it is unclear how hospitals should "identify patients who are unlikely to benefit from critical care intervention." Perhaps this is merely describing the exclusion criteria explained below that statement, but this could cause confusion.

Furthermore, the guidelines say "[p]atients, in general, are excluded from consideration for critical care" in certain others circumstances, in addition to those we discuss above. One situation is when a patient has a "low probability of survival despite intensive care." The guidelines do not explain how this determination is made, what constitutes "low probability," and whether it only includes an assessment of short-term survivability or whether it includes long-term prognoses. And there is no requirement that this determination be made upon an individualized assessment using the best available objective medical evidence.

Another concern is excluding a patient when he or she "requires resources that cannot be provided." The lack of clarity and specificity is concerning. Does this mean the resources of the hospital, or the resources of the broader service system or health care system in Ohio? This could penalize people with disabilities for reasons beyond their control.

And finally the guidelines state that a patient can be excluded from care when the patient's "underlying illness has a poor prognosis with a high likelihood of death." This too is ambiguous, and suffers from the same problems we described above regarding underlying disabilities or conditions. There is also no time limitation on when death is highly likely to occur; compared to short-term survivability, long-term predictions are notoriously difficult to predict and inaccurate.

2. <u>Hospitals should accommodate the needs of people with disabilities to ensure equal access to their services, care, and equipment.</u>

Hospital staff must accommodate the needs of people with disabilities. For example, a person may have limitations in expressive or receptive communications (like a person with autism, as noted above, 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.

3. The requirement for a patient to show evidence of improvement within a specified amount of time, and the focus on saving "the most lives possible in the shortest period of time," may discriminate against individuals with disabilities who might need a longer time to recover.

People with disabilities may need more time to recover than others. As mentioned above, the ADA requires reasonable modifications to hospitals' policies to avoid discrimination on the basis of disability. A strict requirement for reassessment of one's SOFA score after 48 hours of "trial of therapy" (see flowchart on page 25) may penalize many people with disabilities.

4. The strategy of reallocating ventilators to patients who will use fewer resources could discriminatorily impact individuals with disabilities.

Though the guidelines say that allocation-of-scarce-resource decisions should not be made based on stereotypes and subjective judgments about one's quality of life, we are worried that decisions to reallocate ventilators from people with disabilities to those who would use fewer resources would invite these implicit or unconscious biases against people with disabilities.

5. The guidelines also lack a process for patients to appeal decisions—which can be an effective tool for challenging inherent bias.

Patients and their families should have recourse to challenge decisions made by hospitals that exclude them from critical care treatment. This is needed to ensure accountability and transparency.

Conclusion

We look forward to speaking with you in greater detail on Monday morning about the above concerns and others created by the guidelines. We remain hopeful that we can amicably resolve our concerns and ensure your members comply with their obligations under federal law to avoid discrimination against people with disabilities.

Respectfully,

Kevin Truitt
Attorney at law