

We have the legal right of way.

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Dr. Francis:

We appreciate your willingness to speak with us earlier this week regarding the ongoing public health crisis created by COVID-19, Ohio hospitals' rationing care protocols, and broader issues involving people with disabilities and equal access to health care.

We are pleased that the state issued guidance last week for "Standards of Care for Vulnerable Populations." This guidance represents a solid foundation. To protect people with disabilities from discrimination, more clarity and specificity is needed. Here are some of our suggestions to ensure people with disabilities are protected from discrimination:

- The guidance should contain a strong statement prohibiting categorical exclusion criteria based solely on diagnosis or condition in hospital rationing care protocols. This type of exclusionary criteria is unnecessary 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.
- Clarification should be added that modifications must be made to the SOFA (sequential organ failure assessment) and Glasgow Coma scoring systems to ensure that survivability is not underestimated for people with disabilities due to underlying conditions unrelated to their ability to respond to treatment. Baseline levels of impairment existing before the acute care episode (like communication limitations, or a need for assistance

- with activities of daily living) should not act as a penalty. Further, mechanisms must be in place to ensure implicit biases are not factors.
- "Patient survivability," a phrase in the current version of the state's
  guidance, should be changed to "short-term survivability" (i.e., six
  months). Long-term survivability is notoriously difficult to predict
  accurately, and is susceptible to discriminatory assumptions and
  stereotypes about people with disabilities. Maximization of "life-years" is
  similarly problematic.
- In listing broad non-discrimination principles, the state's guidance should warn against language in hospitals' protocols that prioritize "young" or "healthy" patients over those who are "older" or "sicker," who tend to have disabilities.
- The state's guidance should **prohibit penalties against people with disabilities** because they may require the use of greater treatment
  resources, or more time to recover than others. The state should also flatly
  prohibit reallocating a person's personal ventilator.
- The state's guidance regarding accommodations to a hospital's visitation restriction policy is too narrow. There are many more instances where a patient with disabilities may need a family member, provider, or advocate, such as to facilitate communication, assist in making important decisions, or for behavioral support needs.
- Finally, the state's guidance should ask individual hospitals to establish an appeals process for transparency and accountability.

While also a good starting point, the Ohio Hospital Association's guidelines are insufficient because they do not resolve many of the issues stated above, include some problematic language (such as exclusionary criteria), and member hospitals are not required to follow the guidance. Because of this, hospitals have individualized plans, some of which may be inadequate and could place people with disabilities at risk. Ohioans with disabilities are especially at risk because there is, unfortunately, a history of bias within the medical profession based on stereotypes about people with disabilities.

The stakes are high, and the state's continuing leadership is imperative. Baseline guidance to ensure people with disabilities have equal access to care and treatment in hospitals is consistent with the state's exercise of authority over hospitals and health care systems during this state of emergency.

We would be happy to work with you on further revisions to the state's guidance to meet this need, and look forward to our next conversation.

Respectfully,

KQ.

Kerstin Sjoberg Executive Director

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