



April 13, 2020

Dear State Emergency Medical Advisory Committee:

At the outset the Survival Coalition wishes to thank this Committee for the opportunity to comment on the recommendations made by the Ventilator Allocation Workgroup. We recognize that time is of the essence in developing these guidelines. We appreciate the time and thoughtfulness this Committee and the Workgroup have devoted to this critical issue.

We have reviewed the product of the Ventilator Workgroup and think there is much within it with which we agree. There has been a clear attempt to be fair and to avoid disability discrimination. The guidelines have the advantage of being based largely on objective measures that can be evaluated and applied by triage teams. As you will see from our comments below, we think one of the objective measures needs to account for pre-existing disabilities, and determination of survivability needs to be handled with particular care. But for the most part, there is little opportunity for subjective assessment, which is where people with disabilities tend to be disadvantaged.

We have the following specific comments.

Quality of Life or Cognition Not a Factor

We are very pleased to see the strong statement in Part 1 of these guidelines that states:

Triage practices applied in the setting of severe critical care shortages should not be influenced by judgements concerning patients' quality-of-life or functional limitations upon recovery. This includes judgments about the patient's quality of life (due to cognitive or functional disability) before the need for critical care or subsequent to the need for critical care.

We request that when the Committee incorporates the Workgroup's recommendations into its own policy statement that the above statement be prominently included in it. At present the statement, though a consensus one, is included in the part of the report relating to items upon which there was not "uniform agreement." The lack of agreement appears to be on whether persistent vegetative state should or should not be a criterion, not whether quality of life should be. We do not want this critical consensus statement to be lost because it was mislabeled in the Workgroup's report.

Along those same lines, we are pleased to see that the medical criteria for allocation do not include diagnosis, cognitive functioning, or any other factor that explicitly disadvantages a person with a disability as compared to a nondisabled person. The Workgroup is to be commended for attempting to create criteria that were based on objective, individualized medical data.



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SOFA and PELOD Scores are Potentially Discriminatory

While there is no explicitly discriminatory criteria in the workgroup's recommendation, the use of the SOFA (sequential organ failure assessment) score as a criterion may have a discriminatory effect on people with disabilities. The SOFA is a tool designed to assess whether a person's body systems are failing due to sepsis. The problem with using a raw SOFA score for allocating ventilators is that the score does not differentiate between organs/systems that are affected acutely because of an acute condition and those that have been chronically functioning at a lower level because of a person's underlying disability. In other words, a person with a disability might start out with a baseline SOFA score that makes it much more likely that they will reach a SOFA 11 much quicker than a non-disabled patient that may actually be significantly more ill.

Having said that, we do not believe the SOFA score should be deemed an inappropriate marker for predicting likely survivability. We believe the SOFA threshold should be adjusted by the triage team when the patient has a preexisting disabling condition that would elevate the SOFA score but that is not related to, or a legitimate factor in determining, survivability of COVID-19. A very recent article published by the Hastings Center describes the issue:

Instruments designed to evaluate short-term survival probability for typical patients may require reasonable modifications for people with underlying disabilities. For example, many state plans rely on the use of the Sequential Organ Failure Assessment (SOFA), a measure designed to predict short-term mortality, to assess relative survival probabilities. While the use of the SOFA is not unacceptable, state plans must include provisions to ensure that reasonable modifications are made for those whose underlying impairments result in the SOFA penalizing them for their baseline level of impairment prior to the acute care episode.

The Glasgow Coma Scale, a tool for measuring acute brain injury severity, is an element of the SOFA. If administered in its standard form, a patient with a pre-existing speech disability who cannot articulate appropriately intelligible words could achieve a maximum score of 12, adding at least two points on the SOFA. The higher the score, the lower the estimated likelihood of survival. Patients with pre-existing motor impairments are also disadvantaged by this measure — full scoring on the motor response section requires moving in response to verbal commands.

A pre-existing interfering factor should ideally result in a "non-testable" score in this situation, meaning that only the trend (rather than the total score) should be reported. But state and provider level plans have not provided clarity on how to approach such scores within the SOFA. Plans must clearly indicate how instruments like the SOFA should be modified to hold patients harmless for



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underlying disabilities not documented to be relevant to short-term survival in the context of Covid-19.¹

The model presented by the Workgroup does not account for this problem. As suggested in the above article, the triage teams should be instructed to enter a “nontestable” score for the relevant organ system affected by the pre-existing disability, but not relevant to short-term survival. Another solution, though less desirable, would be to adjust the SOFA threshold upward for patients with pre-existing disabilities. Using the person with a pre-existing speech disability as an example, the SOFA ventilator threshold could be adjusted upward by 2, so from 11 to 13. Whichever method is chosen, we have confidence that triage teams will have sufficient expertise to make these individualized adjustments when appropriate if they are specifically instructed-and permitted-to make the adjustment. The need to make this a specific part of triage team training is discussed below.

A similar problem exists in the PELOD, which, for example, also uses the Glasgow Coma Scale as one of its tests. Triage teams should likewise be prepared to make necessary adjustments to a child’s PELOD (pediatric logistic organ dysfunction) score so as to eliminate the potential discriminatory effect of simply using the raw number.

Survivability of Less Than One Year is Subjective and Problematic

Using survivability of less than one year post-COVID is not an unreasonable time period to use given that some time period has to be used. It is far preferable than using life expectancy, which suffers from all the maladies indicated by the Ventilator Workgroup. The problem with using one-year is that, as Dr. Fost candidly admitted last Thursday, there is no objective way to determine whether a person will live one year. Which means that any triage team prognostication will be a guess, albeit a somewhat educated one. In our experience, people with disabilities generally don’t do well when medical professionals start guessing about how long they might live. We see no clear way around this problem. Disability sensitivity training of the triage team is the only way to manage this risk. Training of triage teams is discussed below.

Appeals Must be Permitted

We disagree with the Workgroup’s recommendation that there be no appeal of the Triage team decision. This is a life or death decision. A person who feels that incorrect data has been used to arrive at the decision must have an opportunity to have a third party evaluate that claim. Triage decisions may be made quickly and mistakes will happen. A person should not die because of one. It is possible to create a fast appeal system that protects a person’s basic constitutional due process rights. The appeal system should be explained to all patients and their representatives at admission and again if a triage decision results in a person being denied, or losing access to, a ventilator.

¹ “When It Comes to Rationing, Disability Rights Law Prohibits More than Prejudice,” Ari Ne’emen, 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/>

Removal of Ventilators Requires Additional Considerations

Removing ventilators from patients who already have them based solely on the criteria contained solely in the guidelines is problematic. The patient's response to treatment using the ventilator should be considered as an additional factor when the Triage team is deciding whether to withdraw a ventilator. It would be unwise and unfair to take a ventilator away from someone just as that person begins to recover from the most dangerous phase of the illness. For people with disabilities whose recovery might be somewhat slower, allowance should be made that accounts for that fact. In other words, the criteria developed for withdrawal should accommodate for disability.

Triage Team Training

Any training of physicians or triage teams about how to allocate scarce resources in providing treatment during this epidemic should also include non-discrimination training. Specific disability sensitivity training will reduce the likelihood that any triage team decision will be unknowingly discriminatory. As stated above, triage teams need to be aware of the weaknesses in the SOFA and PELOD scoring systems and need to be trained on how to account for them when a person with a disability presents with a pre-existing condition that is not related to short-term survivability. They also need to be specifically trained on recognizing and eliminating possible bias when determining whether a person with a disability is likely to survive for less than one year. As stated above, there is no known objective way to make this prediction. Triage teams must not assume that any specific diagnosis or disability automatically indicates a poor prognosis for near-term survival or an inability to respond to treatment: people with disabilities regularly outlive the prognoses doctors ascribe to them, often by decades. There must be a thorough, individualized review of each patient. We think patients with cystic fibrosis are at particular risk when making the survivability determination.

Other Recommendations

As the State Disaster Medical Advisory Committee continues its work on various issues related to the pandemic, we ask it to observe certain other considerations related to patients with disabilities. They include the following:

- Reasonable modifications must be made where needed for a person with a disability to have equal opportunity to benefit from the treatment. These include interpreter services or other modifications or additional services needed due to a disability.
- Providing effective communication to individuals with disabilities who are patients or family members of patients is critical to ensuring compliance with federal law. Without effective communication, the patient's autonomy and ability to participate in their care is taken away and doctors risk substituting misplaced assumptions and biases about the individual with a disability in place of verifiable information and medical history.

- If the individual requires an accommodation that involves the presence of a family member, personal care assistant, communicator, or similar disability service provider, who is knowledgeable about the management of their care and could assist them with communicating their needs, or assist them during their hospitalization, this should be allowed provided that proper precautions can reasonably be taken to contain the spread of infection. This is absolutely critical at admission. Overburdened health systems will not have time to get to know and understand a person with a complex disability. They will need input from people who know them well to at least have a basic understanding of how the person communicates, what makes them afraid or upset, how they manifest or express pain or worry, and how best to soothe the person or manage resulting behaviors.

The visitation policy that we believe should be adopted by the Committee comes from Rush Hospital in Chicago and provides:

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 similar 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.²

Community Engagement

We urge the SDMAD to make significantly better efforts to include the interested public in discussions regarding policies and protocols as its work moves forward. We fully recognize that time is of the essence right now. But that should not prevent people from actively participating in decisions that may determine whether they live or die. The Ventilator Workgroup's effort to engage the public was, at best, tepid. The meetings of the SDMAC have thus far provided no opportunity for public input. Documents which the Committee has access to were not shared with the public until after the meeting was adjourned. So far there have been statements made supporting the need for community engagement, but precious little actual opportunity. Because the work of this group is so critical and its results will have so much impact on people's lives, the

² Available at: <https://www.rush.edu/patients-visitors/covid-19-resources/rush-coronavirus-covid-19-patient-and-visitor-updates#visitor>

The state of Oregon has adopted a similar policy: <https://shredsystems.dhsoha.state.or.us/DHSForms/Served/le2282.pdf>



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group must change its approach and provide opportunities for public comment and input, and when that is given the Committee must be receptive to it.

Any document that will be discussed by the Committee needs to be posted with the meeting agenda or as soon thereafter as the document becomes actually available to the Committee itself. Written public comment should be encouraged and any written comments should be distributed to the Committee members as they are received. Events are moving quickly and Committee members need to know what people are thinking about as they vote on proposals, not afterwards. Ideally, a time for comment (oral or through other means) should be included on the agenda of each of the Committee's meetings. Reasonable limits on the time for comment can certainly be imposed.

Any committee decision that advises on allocation of medical resources during a shortage must be made publicly available and widely distributed to stakeholders, including hospital administrators, medical professionals, state and local disability organizations including the Protection & Advocacy network (Disability Rights Wisconsin), The Arc of Wisconsin, the Centers for Independent Living, the UCEDD (Waisman Center) and the Board for People with Developmental Disabilities. In addition, Aging groups and groups representing vulnerable populations should be included.

Expand the Committee Membership to Include Specific Disability Expertise

As we suggested in our initial comments last week, we believe the Committee would benefit from inclusion of a member who has specific experience with people with disabilities in health care settings. The two people we suggested were Marcia Stickel or Leann Smith. Their qualifications and contact information were included in our earlier comment. Both have indicated a willingness to serve should they be invited.

Thank you for consideration,

Survival Coalition Co-Chairs

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