April 15, 2020

Dear Paul:

Thank you for the opportunity to provide our input in the document entitled, "Allocation of Critical Care Resources During a Public Health Emergency " issued by the NJ Department of Health on April 11, 2020. Thank you for the opportunity to participate in the phone session. We appreciate the efforts of the Governor in regard to this sensitive issue. As always, thank you for all of your assistance.

The document was distributed to the staff from the Alliance Center for Independence as well as 19 advocates with disabilities and/or family members in the community, which we work closely with.

The following are the highlights of the feedback/recommendations we received:

* Allocation of Critical Care Resources During a Public Health Emergency document seems to adequately meet the Guidance that HHS OCR released on March 28.
* The document deliberately avoids categorical allocation exclusions several times throughout the document and it is careful not to explicitly state diagnoses as exclusion criteria.
* It ensures that patients will have access to critical care resources even if their own hospital is running low. Patients will be brought to institutions that have the resources needed or critical care resources will be brought to them from neighboring institutions. (Family members and guardians need to be informed of transfer)
* It recognizes that considerations of quality-adjusted life years (QALY's) is not an appropriate way to determine how resources are allocated for patients. Reliance on this " could lead to subjective, discriminatory decisions, particularly related to those with disabilities.
* Ethical goals of the allocation framework page 3
* 4. ensure that discrimination based on race, creed, color, national origin, nationality, ancestry, marital status, domestic partnership or civil union status, sex, affectional or sexual orientation, gender identity or expression, disability, place of residence, socioeconomic or insurance status is explicitly avoided (**How will this be enforced? What do you do if you feel you were discriminated against?)**

 **Composition of Triage Teams and Triage Review Committees:**

* While the document states there should be a minimum of 3 people on each of these teams, from what departments they may come from, how long their shifts are and their proximity to patient care -there is no mention of the demographic makeup of the team, or even the suggestion of ensuring diversity. If these teams are homogeneous in nearly every way except their professional titles, there unfortunately will be an implicit bias in the decision-making process no matter which quantitative, valid scaling tools are used in the scoring process. It is of greater concern to me for the Triage Review Committees who are charged with handling appeals when scarce critical care resources are to be withdrawn.
* The Triage Review Committee should include a representative of the patient, or a family member or guardian. Consideration needs to be made for someone with a disability to be on the committee as well.
* Training to the "triage teams and hospital/system decision-makers and health care staff in advance of implementation of adopted allocation policies" should include information about people w/ disabilities / lives worth living.
* 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.
* There should be the creation of multiple triage teams to ensure unbiased decision making.

Ethical goals of the allocation framework

* 4. ensure that discrimination based on race, creed, color, national origin, nationality, ancestry, marital status, domestic partnership or civil union status, sex, affectional or sexual orientation, gender identity or expression, disability, place of residence, socioeconomic or insurance status is explicitly avoided (**How will this be enforced? What do you do if you feel you were discriminated against?)**

 **Triage Prioritization of Patients Regardless of Presentation:**

* Because the triage prioritization will be used on all patients requiring critical care/ventilation, not just those presenting with Covid, it's vitally important that the tools used to assign priority scores do not negatively impact those with disabilities. This document lacks clear guidance regarding how pre- existing conditions are handled in the scoring process- when full scoring in several sections of SOFA depend on moving or verbalizing in response to verbal command.

**Ethical goals of the allocation framework**

The document contains language about avoiding discrimination (discrimination based on race, creed, color, national origin, nationality, ancestry, marital status, domestic partnership or civil union status, sex, affectional or sexual orientation, gender identity or expression, disability, place of residence, socioeconomic or insurance status is explicitly avoided) How will this be enforced? What are the procedures to follow if one is alleging discriminated?

**Communication of triage decisions to patients and families**

* Shouldn't the patient be in on the discussion before a decision is made? And not just merely informed of the decision. See second bullet under Composition of Triage Teams above.

 **People who enter the hospital using their own mechanical ventilation devices**

* It is common practice for medical facilities to disallow the use of non-hospital issue ventilation devices upon admission. Given the scarcity of said devices, how will such patients be handled? Or, ideally, if the state of NJ already has already issued guidance on this topic- in times of equipment scarcity specifically- it should be referred to in this document. Although, open loop ventilation is problematic because it doesn't contain the airborne respiratory particles. Closed circuit mechanical ventilation does.

**Training**

* Training modules should be reviewed by a bioethicist specializing in disability. Providers will likely operate from what they recall from a short training rather than a densely worded multi-page protocol document. For example, during the training, will adequate and clear information be presented on the difference between QALYs and life years saved. This document doesn't clearly address the distinction between the two well enough. Ensuring triage teams understand the difference matters for the disabled community.

**Trial therapeutic periods**

* The language around this component is subjective, vague and concerning. From the document: "Therapeutic Trial duration will also need to be tailored for other non-pandemic diseases and patient contexts, given the concern that patients with certain disabilities may need longer trials to determine benefit. The trial duration should be modified as appropriate if subsequent data emerge about the clinical course of the pandemic illness.
* How is the determination of who receives longer trial durations made? While this document does not include disabilities as exclusion criteria per se, (because of the HHS OCR guidance) they offer no objective clarity for the parts of this guidance that matter the most to our community. In name it is written that people with disabilities can be given longer trials to determine if a course of treatment is beneficial, but no guidance is offered on when, and in what circumstances that may be offered....so it probably won't be.

**Long-term survival should be omitted from the assessment**

* The NJ Department of Health should look at New York's ventilator allocation guidelines, which explicitly reject the use of long-term survival, arguing that the definition of survival should be “based on the short-term likelihood of survival of the acute medical episode and is not focused on whether a patient may survive a given illness or disease in the long-term"

**References to "Disabled and Aging"**

* How are these terms defined?

**Other scoring considerations**

* While it's important to prioritize “people central to the public health response" this would need to be better defined.

**Establishment of State Bioethics Committee**

* Disability advocates who are regarded as subject matter experts in the field of disabilities and access and functional needs serve on the bioethics committee or as advisors to the committee.
* The names of several advocates have been put forth thus far, including Javier Robles, a professor at Rutgers University, and Kelly Boyd, the DAFN planner at NJOEM. Ms. Boyd also spent time on a ventilator and has written articles on the subject**.**

**Plain Language**

* Once thisAllocation of Critical Care Resources During a Public Health Emergency policy becomes official and ready to be made public a plain language version of it should be available for families, guardians and patients.

Again, thank you for the opportunity to provide input on this crucial document. If you have any questions, please feel free to contact me or Luke Koppisch.

Stay well,

Carole Tonks

Executive Director

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