



DISABILITIES LAW PROGRAM

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By Email

Secretary Dr. Kara Odom Walker, Dept of Health and Social Services
Dr. Karyl Rattay, Director, Division of Public Health
Dr. Richard Hong, Medical Director, DPH Office of Preparedness

Dear Secretary Walker and Doctors Rattay and Hong:

We appreciate Delaware's ongoing response to the COVID-19 crisis, including development of the recently shared Delaware Crisis Standards of Care (hereafter "DE CSC"). What is abundantly clear is that all possible efforts must be made to avoid the use of any rationing of care policy, and Delaware's leadership has certainly been addressing the crisis at full throttle, hopefully to avoid that necessity. As I stated in my previous correspondence, access to the full range of medical care is a matter of immense importance to people with disabilities, whose lives have been historically undervalued, especially by the medical community.¹

This letter contains specific alterations and additions we believe are required in order for the DE CSC to comply with federal law, and to make it internally consistent. We address those items in more detail below, along with other specific recommendations intended to ensure the Delaware's guidance: 1) is consistent with federal law and the recent OCR bulletin; 2) avoids criteria which would lead to discriminatory assumptions or unconscious bias in the provision of lifesaving care,² and includes safeguards against such influences in triage decisions; and 3) upholds the policy's provisions that are intended to avoid inequities in the allocation of care to individuals based on disability, age, race, or other protected status.

¹ See, Medical Futility and Disability Bias, National Council on Disability, 2019, <https://ncd.gov/newsroom/2019/NCD-study-medical-futility>. Also, OCR Complaint Against Washington State Department of Health, https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf, Pages 9-11.

² The prevalence of unconscious bias in the provision of health care generally is well documented. See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5333436/> (meta-analysis of 49 articles on the impact of implicit race and gender bias in the provision of medical care concludes that "healthcare professionals exhibit the same levels of implicit bias as the wider population" and that bias is "likely to influence diagnosis and treatment decisions and levels of care in some circumstances . . .;" see also <https://www.aafp.org/afp/2017/0801/p192.html> ("[f]alse assumptions about patients' quality of life can affect prognosis" and even "result in premature withdrawal of life-preserving care."

Use of strict utilitarianism as a guiding principle or operational policy is illegal, and should be eliminated.

The United States Department of Health and Human Services Office of Civil Rights (“OCR”) Guidance from March 28, 2020 clearly states that people with disabilities are to be protected from “ruthless utilitarianism,” which is illegal under our civil rights laws.³ Nevertheless, the Executive Summary on page three of the DE CSC describes the policy as having a utilitarian framework. Likewise, Sections 1.1, 3.1.7(which again uses the term “utilitarian”), 7.6.1D and 7.6.2 B all state that the clinical goal under the policy is to do the greatest good for the greatest number, allocating “to those most likely to survive in order to save the largest number of people.”

A strictly utilitarian approach will result in people with disabilities getting diminished access to care. Likewise, such an approach will not address health care disparities among people of color and others living in poverty who frequently have chronic illnesses such as hypertension, diabetes, severe asthma, or COPD. They too will fall “down the list.”

Use of utilitarianism as a guiding principle is also inconsistent with many other elements of the DE CSC. Section 3.1.10 states that vulnerable populations are to be “provided equal access to care irrespective of medical, physical, cognitive or emotional disability.” Section 3.1.11 limits consideration of chronic diseases to those affecting mortality from the acute illness (currently COVID-19). Sections 7.6.2 D(i) and E prohibit triage officers from discriminating between populations based on disability or other vulnerability. Section 7.6.2F prohibits discrimination based on race, gender, infectious disease status or other personal or social characteristics. *It inexplicably fails to include disability as a protected class and needs to be amended.* Nevertheless, these are standards of fairness and equal access, and they are not utilitarian.

Consequently, our strong recommendation is that the word “utilitarian” be removed from the DE CS and that the goals to provide the greatest good for the greatest number be refined to state that any allocation or triage policy or practice must be consistent with anti-discrimination laws covering all protected classes, including disability.

³ This bulletin is available at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>; see also, <https://www.disabilityscoop.com/2020/03/30/trump-administration-says-disability-no-reason-to-deny-covid-19-care/28065/>. The DE CSC should explicitly reference as binding on Delaware hospitals the US Health and Human Services’ Office of Civil Rights Bulletin prohibiting disability discrimination in HHS funded health programs, including the delivery of lifesaving care during the COVID-19 outbreak. OCR Complaints related to health care rationing policies filed against the states of New York, Pennsylvania, Washington, Alabama, Tennessee and others can be found at <https://www.centerforpublicrep.org/covid-19-medical-rationing/>

Other states have taken a more nuanced approach to the goals of their Crisis Standards of Care, which is to maximize outcomes for populations of people, taking into account that not all groups in American society will present on equal terms to health care facilities. For example, the April 2020 Massachusetts policy that is cited in the DE CSC has as its overarching goal equitable access to care. Minnesota also takes a multifaceted approach, focusing on three ethical objectives: one, protect the population's health; two protect public safety and civil order; and three, strive for fairness and protect against systematic unfairness.⁴

Replace vague criteria that are likely to screen out or disparately impact people with disabilities.

Delaware should eliminate triage criteria which score or prioritize patients based on survivability, better outcomes, or that otherwise use consideration of prognosis of underlying disease or co-morbidities in allocating resources. These criteria dramatically increase the likelihood that individuals with disabilities will be denied lifesaving care based on discriminatory assumptions about their quality of life, or overall life expectancy. Even validated instruments like the SOFA can only begin to assess short term survivability – namely survivability to discharge.

The proposed DE CSC use several of these vague standards. First, Section 7.6.1 D lists as a principle maximizing resources to benefit people “with the best chance of survival.” Section 7.6.2B indicates that Triage Tools should allocate resources “to those most likely to survive.” Section 7.6.2G indicates that the Triage Tool should be designed to allocate resources “with a better predicted outcome.” Section 7.6.2I.ii affirmatively lists prognosis of underlying diseases and any severe limitations on life span as a priority consideration.

These Sections provide no objective, reliable or consistent means of informing or guiding decisions on “outcome”, “survival” or define what “severe” means. Does survival or use of prognosis mean a consideration of long term survival that might include the impact of co-morbidities or other pre-existing conditions that were disabling to the individual before they got sick?⁵ Or does it mean survival of COVID-19?

⁴ <https://www.health.state.mn.us/communities/ep/surge/crisis/ethics.pdf>, Page 18

⁵ Such an analysis runs afoul of the OCR Guidance, and is inconsistent with Sections 3.3.11 and 7.6.2 D which limit consideration to current status of underlying medical diseases as they relate to the acute illness presented (e.g. COVID-19).

Consideration of short term survivability of the acute illness that would necessarily include an assessment of the patient's condition on admission is appropriate; projections of long term survivability are not. Consideration must be based on the prospect of surviving the condition for which the treatment is designed—in this case, COVID-19—and not other disabilities.⁶ Such criteria will harm not only people with disabilities but also populations whose health and longevity are already negatively impacted by inequities in access to care (people with psychiatric disabilities; communities of color; LGBTQ individuals). These criteria are inconsistent with and undermine the goals of equity, transparency and fairness in the rationing process.⁷

Therefore, we recommend the above criteria be eliminated from the DE CSC and instead include the following statement: “Intermediate or long term prognosis or survival may not be factors in determining priority for emergency lifesaving treatment. Attempts to predict long term prognosis, especially for persons with disabilities, can lead to erroneous, inconsistent, and subjective decision-making in violation of federal antidiscrimination laws. Triage decisions should be governed by individualized assessments of the patient's potential for survivability to discharge.”

Emphasize that all triage decisions must result from individualized assessments based on objective medical evidence.

Even validated medical assessment tools can be vulnerable to unconscious bias in their application. For instance, if Delaware allows the SOFA (Section 7.6.2I.i) to lower an individual's priority for life saving care based solely on the presence of chronic, but stable underlying conditions, like diabetes, developmental disability or acquired brain injury, it risks running afoul of federal antidiscrimination laws and directives from OCR.

DE CSC should include the following statement with regard to use of the SOFA or other mechanisms in triage scoring: “Triage teams must avoid penalizing individuals with chronic but stable underlying conditions, including individuals with disabilities, when calculating SOFA scores. Baseline levels of impairment, prior to the acute care episode, should not increase SOFA scores unless objective medical evidence, interpreted by a medical professional with expertise necessary to exercise professional judgment under usual standards of care, demonstrates that those conditions directly impact an individual's short term survivability with treatment.”

⁶ The American College of Physicians has also rejected the use of long term prognosis or “life years saved”, instead recommending that hospitals make resource allocation decisions “based on patient need, prognosis (determined by objective scientific measures and informed clinical judgment) and effectiveness (i.e., the likelihood that the therapy will help the patient recover). Allocation of treatments must maximize the number of patients who will recover, not the number of “life-years,” which is inherently biased against the elderly and the disabled. <https://www.acponline.org/acp-newsroom/internists-say-prioritization-allocation-of-resources-must-not-result-in-discrimination>

⁷ See, COVID-19 Triage and Disability: What Not to Do. Joseph Stramondo, PhD, Bioethics.net, March 30, 2020, available at ...<http://www.bioethics.net/2020/03/covid-19-triage-and-disability-what-not-to-do/>

Require that reasonable accommodations/modifications of the triage protocol be considered for people with disabilities and eliminate consideration of long term resource needs.

Certain triage criteria, such as limitations on how long patients may stay on a ventilator without demonstrated improvement, may have a disproportionate, negative impact on individuals who are no less likely to recover, but may do so more slowly due to a pre-existing disability. The DE CSC should make clear that federal laws requiring reasonable accommodations remain in effect even when crisis standards of care are invoked. Treatment allocation decisions cannot be made based on the perception that a person's disability will require the use of greater treatment resources.

Reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment. We recommend modifying Section 7.6.2 I. iii to include the following statement: "Treating doctors and triage teams must consider reasonable accommodations to triage protocols for individuals with disabilities, including the extension of ventilator trial periods, when patients are expected to recover, but may require additional time to demonstrate effective progress because of their disability."

Section 7.6.2I.iv contemplates denying care based on a determination that a person's ongoing "long term resource needs cannot be met." This particular provision is especially troubling and violates OCR guidance and discrimination laws. How would a triage officer know what the person's long term needs are, or whether they are or will be available once the acute illness has resolved? This provision leaves people with complex or severe disabilities particularly vulnerable to discriminatory rationing of care and should be eliminated. Considerations of long term survivability or larger than average utilization of resources are not appropriate and will lead to discrimination.

Other matters of concern:

1. Provide patients with disabilities with effective methods of communication, which can include modifications of no visitor policies to allow in-person support.⁸
2. Individuals who own and routinely use ventilators in the community may require acute hospital care during the pandemic. Given concerns around the country regarding the discriminatory removal of ventilators from these individuals, the DE CSC should include the following statement: "Individuals presenting for hospital level of care will not be subject to the automatic withdrawal, removal or redeployment of personal lifesaving equipment, including ventilators, based on discriminatory assumptions about their intensity of need or likelihood of recovery."

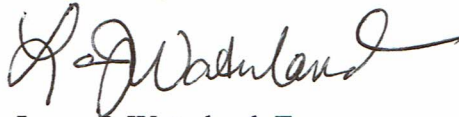
⁸ See, e.g. COVID-19 visitor policy of Rush University Medical Center, Illinois, available at <https://www.rush.edu/patients-visitors/covid-19-resources/rush-coronavirus-covid-19-patient-and-visitor-updates>

3. Ensure an accessible, transparent and accountable appeal process.⁹ The DE CSC does not mention this essential feature of any plan.
4. Ensure broad data collection and review by an independent panel once the crisis period has passed, that includes representatives from marginalized communities.
5. Ensure transparency by mandating that health care systems and facilities publish or otherwise make publically available triage protocols and appeals processes.

People with disabilities deserve equal access to life-sustaining treatment, even within the context of scarcity. We urge you to make these modifications as quickly as possible to ensure that our state does not give sanction to impermissible discrimination that would corrode the practice of medicine and threaten the trust our current crisis requires us to place in health policymakers.

We appreciate your time and assistance with this important matter.

Respectfully,



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cc:

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⁹For a description of an effective appeals policy for patients, refer to U of Pittsburgh Protocol, Page 4.
https://www.ccm.pitt.edu/sites/default/files/UnivPittsburgh_ModelHospitalResourcePolicy.pdf.