Sent via e-mail to: jdrummond@mhanet.com

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Ms. Jane Drummond, Esq.
General Counsel and Vice President of Legal Affairs
Missouri Hospital Association

Dear Ms. Drummond,

Thank you for the opportunity to provide input and guidance on, "A Framework for Managing the 2020 COVID-19 Pandemic Response (Framework)." We understand this document provides guidance to hospitals with recommendations that each healthcare facility develop plans to address altered standards of care. Our focus when reviewing the document is ensuring that the guidance provided to hospitals does not contain restrictions on medical care that would have unintended discriminatory consequences for people with disabilities, many of whom are at high risk of contracting COVID-19, death, and ongoing complications if they survive.

It is essential that healthcare institutions operate within an ethical framework and consistent with civil rights laws that prohibit discrimination in the delivery of healthcare. Specifically, in allocating healthcare resources or services during public health emergencies, healthcare institutions are prohibited from using factors including, but not limited to, race, ethnicity, sex, gender identity, national origin, sexual orientation, religious affiliation, age, and disability unrelated to near-term survival. Assumptions or stereotypes based on these characteristics serves no meaningful purpose in differentiating between people in the context of healthcare allocation decisions, and, as further detailed below, are unacceptable both from an ethical standpoint, and as a matter of civil rights law.

Significant legal protections are in place to prohibit discrimination in the delivery of healthcare. Healthcare providers in the United States are subject to nondiscrimination mandates. Specifically, federal civil rights laws, including Section 1557 of the Affordable Care Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act Amendments Act (2008), prohibit discrimination in the context of allocation of medical care. These laws provide a mandate to healthcare providers at all times, **including during the current and ongoing COVID-19 crisis.**

We recognize that everyone has been working diligently throughout this pandemic, and in particular during the current surge; and the intent would have been to bring stakeholders together to develop the guidelines outlined in the Framework. While reviewing the Missouri Framework, we noted that the guidance in this document~~,~~ was based on plans from other states, such as the Utah Pandemic Influenza Hospital and ICU Triage Guidelines for Adults (2018 or 2019). However, in August 2020, the federal Office for Civil Rights ("OCR") issued a resolution after the Center for Public Representation and numerous other groups filed complaints about the Utah guidance, which alleged that Utah's plan illegally excluded certain people with disabilities from accessing life-saving treatment, like ventilators, based on their disabilities; and deprioritized others based on their disabilities. "In response to the complaint and engagement with OCR, Utah has revised its Crisis Standard of Care Guidelines to comply with federal disability rights laws and ensure that people with disabilities are not discriminated against even when public health emergencies, such as the COVID-19 pandemic, necessitate the rationing of scarce medical resources."

Most notably, per OCR, hospitals must now provide information on the full scope of available treatment alternatives, including the continued provision of life-sustaining treatment, and **may not impose blanket Do Not Resuscitate (DNR) policies** for reasons of resource constraint. Physicians may not require patients to consent to a particular advanced care planning decision in order to continue to receive services from the hospital. This is the first time OCR has weighed in on this issue.

The following are additional key changes in Utah's policy to avoid discrimination against people with disabilities following the OCR resolution:

- **No Exclusions or Deprioritizing Based on Resource Intensity or Disability Diagnosis:** An individual can no longer be excluded from, or deprioritized for, medical treatment based on the fact that they might require more time or resources to recover or because they have a disability diagnosis or functional impairment. Rather than making assumptions about a patient's ability to respond to treatment based solely on stereotypes, medical personnel must perform an **individualized assessment of each patient** based on the best objective current medical evidence
- **No Long-Term Survivability Considerations:** Utah has eliminated long term survivability as a consideration in treatment decisions, changing its Guidelines to allow medical personnel to consider only "short-term mortality." Survivability is a factor that can be fraught with speculation, mistaken stereotypes, and assumptions about the quality of life and lifespan of people with disabilities.
- **Reasonable Modifications Required:** Utah's Guidelines now require hospitals to make reasonable modifications to the Modified Sequential Organ Failure Assessment (MSOFA)—the tool used to prioritize access to medical treatment—to avoid penalizing people with underlying conditions that are unrelated to their ability to benefit from treatment. The

Guidelines note that other reasonable modifications may also be required to provide equal access to treatment for patients with disabilities.

- **Reallocation of Personal Ventilators Prohibited**: Medical personnel may not reallocate the personal ventilator of a patient who uses a ventilator in their daily life to another patient whom the personnel deem more likely to benefit from the ventilator in receiving treatment."

-https://www.centerforpublicrep.org/news/resolution-of-federal-complaint-filed-by-cpr-and-partners-sets-national-precedent-against-blanket-dnrs-medical-discrimination-on-the-basis-of-disability-during-the-covid-19-pandemic/

As of November 19, 2020, the Utah plan resulting from the August 2020 OCR resolution was further revised and the revisions have been made public. The new revisions remove the age "tie-breaker" language and substitute the following language:

"Tiebreakers: When two patients cannot be distinguished relative to short term outcome after the individualized assessments conducted in Step 3, a tiebreaker may need to be used in order to determine which patient receives the limited resource:

First tiebreaker: When two patients are apparently the same on all other measures at a given point in time, if one patient's clinical trajectory is declining more rapidly than the other patient needing the same limited resource, the limited resource should be assigned to the patient with the less rapid rate of clinical decline, and thus the greatest prospect of short-term survival.

Second tiebreaker: When two patients remain tied after assessment of their respective clinical trajectories, a judgment should be made of which patient has the greater prospect of short-term survival based on additional clinical judgment of patient's record and overall presentation of relevant symptoms, combined with use of recommended assessment tools (https://utahhospitals.org/resources), so long as this judgment is not based on any unlawful considerations of race, color, national origin, disability, age, or sex.

Third tiebreaker: When patients remain tied after consideration of clinical judgment, assign the limited resource by randomization to lottery. Suggested approaches can be found in the toolkit listed above."

While disability groups still have some concerns about how the 2nd tie breaker could be implemented (and the OCR complaint plaintiffs will be monitoring this), the OCR resolution of Utah, with this change, is a good CSC overall.

Missouri's reliance on the Minnesota Healthcare Preparedness Program's guidance is also problematic in part as Minnesota, too, recommends that pre-existing conditions be taken into consideration when determining treatment, such as whether an individual is oxygen dependent or requires dialysis. However, throughout the rest of the document, Minnesota addresses the likelihood of survival of the individual, regardless of pre-existing conditions.

In the section of the Missouri Framework which addresses the ethics of inclusion and exclusion criteria, there is language that is concerning, such as the following: "Common criteria include age, the presence of other diseases or congenital conditions, first-come, first-served, preservation of health care workers or a lottery approach. Each has ethical ramifications," and "During a public health emergency, hospitals may use the presence of other health conditions to score patients but must do so with caution." While indicating that these are considerations where caution should be used, the language throughout this section is subjective and inherently discriminatory against those who have pre-existing conditions and/or disabilities.

We urge MHA to review the current language in its guidance, and revise the recommendations to include development of strong and clear language stating that hospitals **must** avoid discrimination and comply with federal laws, to include civil rights laws that protect individuals with disabilities.

We also have concerns regarding the guidance for hospital visitation policies, as the guidance does not address the needs for exceptions for people with disabilities, who need assistance to get equal access to health care. We understand that hospitals and healthcare offices have dramatically restricted visitors with very few exceptions.

Such policies pose serious and unique challenges to individuals with disabilities who rely on in-person supports both in and out of the hospital, including, but not limited to, individuals with psychosocial, intellectual, developmental, or cognitive disabilities who rely on essential, medically necessary, in-person supports for orientation, anxiety management, interpretation or facilitated communication, and/or assistance with making decisions. Hospitals and doctor's offices must continue to make reasonable accommodations and modifications to policies where necessary, to ensure that people with disabilities enjoy an equal benefit as that offered to others, pursuant to the Americans With Disabilities Act (2008).

We recommend that the guidance in the Framework specify when there may be exceptions for visitors. Rush University Medical Center (RUMC) has one of the better visitor policies, and the exception for visitors for patients with disabilities states the following:

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.

Federal disabilities laws require that each person with a disability be assessed individually according to his or her needs, abilities, and situation.

We realize that time is critical, as the pandemic has rapidly worsened into a crisis mode. **Therefore, we strongly recommend that MHA address the concerns raised above, and revise the Framework for Managing the 2020 COVID-19 Pandemic Response by December 11, 2020.** We are glad to offer any assistance and review of an updated and completed Framework to ensure the guidance offers guidance that does not contradict civil rights laws.

We appreciate the opportunity to comment and make recommendations on this document.

Very respectfully,

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