



August 31, 2020

Governor Doug Ducey
Office of the Governor
State Capitol
1700 West Washington
Phoenix, Arizona 85007

Dear Governor Ducey:

On behalf of the undersigned organizations representing people with chronic conditions and disabilities, thank you for your ongoing efforts to address the COVID-19 pandemic. We write today to comment on the *Arizona Crisis Standards of Care Plan (CSC)* (3rd ed. 2020) and subsequent *COVID-19 Addendum*, activated on June 29th.^{1, 2} We thank the State of Arizona for recognizing the importance of guidance for health care professionals during this time to protect both patients and clinicians but ask the state to revise current guidelines to guard against discriminatory medical care triage practices. Specifically, we ask that you remove recommendations regarding the use of long-term survival estimates when making allocation decisions and that you allow for reasonable modifications to the Sequential Organ Failure Assessment (SOFA) to account for baseline impairment for people with chronic conditions or disability. We urge you to engage with patient and disability rights organizations in the state as Arizona furthers efforts to ensure equitable access to limited medical resources during this time.

We understand that, in response to a previous spike in the number of cases and resulting shortage of intensive care beds and ventilators, the Arizona Department of Health issued a letter on June 6th advising that hospitals fully activate their emergency plans.³ While the number of cases has since decreased, the COVID-19 pandemic continues to present serious risk to Arizona residents, including the patients we represent. According to publicly available data from the Centers for Disease Control and Prevention (CDC), over 182,000 people in the United States have died as a result of COVID-19, including more than 5,000 in Arizona as of August 30th.⁴ Furthermore, over the last seven days, more than 3,300 cases in Arizona have been reported to the CDC. It is important that Arizona has equitable, non-discriminatory allocation guidelines in place should the state reach another point where need outstrips capacity.

¹ <https://www.azdhs.gov/documents/preparedness/emergency-preparedness/response-plans/azcsc-plan.pdf>

² <http://azpha.wildapricot.org/resources/covid-19-addendum.pdf>

³ <https://azdhs.gov/documents/preparedness/epidemiology-disease-control/infectious-diseases-services/coronavirus/hospital-preparedness-covid-19-jun-2020.pdf>

⁴ <https://www.cdc.gov/covid-data-tracker/>

Thank you for recognizing the need for state-wide guidance on how to equitably allocate scarce medical resources, and for issuing a COVID-19-specific addendum. We acknowledge the monumentally difficult task public health officials face when creating allocation guidelines that are both equitable and actionable. We are encouraged that the *COVID-19 Addendum* contains principles stating that patients will not be categorically denied care “based on stereotypes, assumptions about any person’s quality of life, or judgement about a person’s “worth” based on the presence or absence of disabilities.”

However, we are concerned with the addendum’s recommendations on the use of long-term survival estimates and SOFA scores that don’t account for baseline impairments, when prioritizing patients for the allocation of life-saving care. We share the concern raised by disability groups in their July 17 complaint to the HHS Office of Civil Rights (OCR) that the use of unmodified SOFA scores and long-term survival standards may unfairly de-prioritize people with chronic conditions and disabilities, even if they have the same likelihood of immediate survival. We encourage you to prohibit the use of long-term survival measures and include reasonable modifications to the SOFA and other procedures to account for those with a baseline level of impairment prior to the acute care episode.

We urge you to work with our organizations, as well as other patient and disability rights organizations in Arizona, to revise current guidelines in accordance with OCR’s March 28 bulletin to ensure that all patients are evaluated on a case-by-case basis and that decisions about who receives treatment are based on current clinical presentation – regardless of underlying health condition or disability.⁵ It is critical that all patients receive individualized assessments when making determinations on allocating medical resources; health care providers must not assume that the mere presence of an underlying condition or disability indicates poor prognosis or inability to respond to a given treatment. Several of our groups have endorsed additional guidance, written by disability rights professionals, on how to implement the bulletin in states.⁶ We hope this document helps the State of Arizona to revise current guidelines to ensure non-discrimination against the people we represent.

Thank you for all that you are doing to ensure the health and safety of Arizona residents in the midst of the ongoing pandemic. Our organizations stand ready to serve as a resource for your administration as you work to ensure that patients are not unfairly disadvantaged in determining access to scarce medical resources. If you have any questions regarding this letter, or if we may provide further information, please don’t hesitate to contact Rachel Patterson with the Epilepsy Foundation at rpatterson@efa.org.

Sincerely,

American Kidney Fund
Arthritis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation Arizona
National Multiple Sclerosis Society
National Organization for Rare Disorders

⁵ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

⁶ https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf