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May 6, 2020

Roger Severino Director,
Office for Civil Rights U.S. Department of Health & Human Services
200 Independence Avenue, S.W. Washington DC 20201

Re: Addendum to Utah's complaint of Disability Law Center and Jodi Hansen on behalf of Jacob Hansen.

Amanda Longwell

James O'Neill

Jared Fields

Jeff Skibitsky

Jodie Palmer

Kathleen Jacques

Ken Gourdin

Kyli Rodriguez-Cayro

Leslie Francis

Libby Oseguera

Lurena Mead

Mike Chidester

Stacy Stanford

Stephanie Burdick

Dear Mr. Severino:

Thank you for our recent call to discuss the DLC's complaint concerning Utah's health care rationing guidance. As we discussed on our call, the State of Utah recently published the Covid-19 Annex¹ to the 2018 Utah Crisis Standards of Care Guidelines. The 2018 Guidelines remain the basis for crisis care and the Annex provides additional guidance focused on Covid-19. Despite our recent complaint, the Annex does not ameliorate our concerns about the potential for discrimination against people with disabilities. We reiterate our allegations regarding the 2018 Guidelines and we ask you to also investigate our additional concerns about the Annex.

As discussed below, both the Annex and the 2018 Guidelines illegally discriminate against people with disabilities and fail to provide clear guidance to health care providers. The 2018 Guidelines and Annex contain conflicting information except to direct providers to place individuals with health conditions at a lower priority for care. While Utah has not experienced a lack of hospital beds or respirators, a second wave of infections is very possible in the absence of effective treatment or a vaccine. It is vital, given the current pandemic, that the State of Utah put forth clear guidance to health care providers that ensures people with disabilities will not be devalued when determining how to utilize health care resources.

In light of the State's additional Covid-19 guidance we would like to amend our complaint to address the State's Annex. We respectfully request you consider our concerns as outlined:

¹*Utah Standards of Care Guidelines: Covid-19 Annex*, The State of Utah, (April 10, 2020), [https://coronavirus-download.utah.gov/Health-provider/Final%20COVID19%20CSC%20Annex%20April%2015%202020%20\(1\).pdf](https://coronavirus-download.utah.gov/Health-provider/Final%20COVID19%20CSC%20Annex%20April%2015%202020%20(1).pdf).

The State's Guidance Includes Categorical Exclusions for People with Disabilities

As we described in detail in our initial complaint, categorical exclusions of people with disabilities based on their diagnosis constitutes disability discrimination. HHS' Office of Civil Rights' recent resolution with the state of Alabama reiterated this legal principle.² As discussed below, Utah's 2018 guidelines and its Annex illegally categorically exclude people with disabilities.

- The 2018 Guidelines contain exclusion criteria for individuals with neurological conditions, severe dementia and neuromuscular disease requiring assistance with activities of daily living. For pediatric patients, the exclusion criteria also include conditions such as cystic fibrosis, chromosomal abnormalities, and children who are unable to sit unaided when it would be developmentally appropriate based on age.
- The Annex provides no guidance on pediatric care other than to state that Modified Sequential Organ Failure Assessment ("MSOFA") does not apply to patients less than age 14. This either puts the State in a position to have no guidance on pediatric care during the pandemic or to utilize the guidance in the 2018 Guidelines. No guidance risks illegal rationing during the provision of care, and the 2018 Guidelines includes the exclusion criteria mentioned above.
- The Annex also explicitly states that non-ICU care will be offered to individuals with acute or chronic neurological conditions, which appears to be a general statement of the exclusions from the 2018 Guidance. Neurological conditions are described only in broad terms which could lead to discriminatory interpretations by providers resulting in the withholding of care for individuals with neurological conditions who would benefit from ICU care.

The State's Annex Relies on Assessment Tools that Deprioritize People with Disabilities for Conditions Unrelated to their Ability to Survive Covid-19

- The 2018 Guidelines indicate that the State is adopting the "UCSCG Patient Prioritization Tool" rather than a MSOFA score method. The Patient Prioritization Tool relies heavily on several principles that are unlawful as pointed out in our original complaint. These factors include, age which the guidelines state expressly are "not meant to indicate the likelihood of survival," and an ASA score that is "a marker for increased comorbid illness and thus a trend toward greater resource utilization."
- Despite the decision to replace the MSOFA with the Patient Prioritization Tool in the 2018 Guidelines, the Annex published by the State reinstates the MSOFA for use during

² *OCR Reaches Early Case Resolution with Alabama After it Removes Discriminatory Ventilator Triage Guidelines*, HHS.gov (April 8, 2020), <https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html>.

the pandemic. Specifically, the Annex states that individuals with a MSOFA score of 11 or greater will be screened out of initial ICU care.³ Additionally, the Annex indicates that the MSOFA can be used to withdraw care from patients currently in the ICU as ordered by the Crisis Triage Officer (“CTO”).⁴ Generally, the categories that determine a MSOFA score relate to underlying health conditions including the use of oxygen and pre-existing liver functioning among many others. In these instances, individuals with disabilities will be screened out of care just as they are under the Patient Prioritization Tool. Further, the Annex states that the efficacy of the MSOFA is in doubt noting, “The predictive ability of MSOFA has not been studied in COVID-19 and we anticipate revising this guideline as data emerges which could enhance the prediction of survivability with COVID-19.”⁵

- Additionally, as pointed out in several other complaints filed on similar topics, the MSOFA is inherently discriminatory towards individuals with disabilities because even when based on individualized medical evidence, instruments like the SOFA may inappropriately penalize individuals with chronic, but stable disabilities. For example, the Glasgow Coma Scale, a tool for measuring acute brain injury severity in the MSOFA, adds points when a patient cannot articulate intelligible words, even if this condition is due to a pre-existing speech disability.⁶ Patients with pre-existing motor impairments are also disadvantaged by this measure which requires moving in response to verbal commands. This is one example, of many possible scenarios, in which people with disabilities will be penalized for their underlying health condition regardless of their Covid-19 prognosis.
- Both the Patient Prioritization Tool and the MSOFA remain highly biased against people with disabilities and make value judgments about the quality of their lives. It remains unclear how these systems work together. The Annex also states that the MSOFA will not be utilized for pediatric cases—indicating that it will certainly be applied to adults.⁷ However, neither policy directs decisions about care to be made based on individual assessment and response to Covid-19 treatment, and are therefore both unlawful and against HHS guidance.

³ *Utah Standards of Care Guidelines: Covid-19 Annex*, The State of Utah, (April 10, 2020), [https://coronavirus-download.utah.gov/Health-provider/Final%20COVID19%20CSC%20Annex%20April%2015%202020%20\(1\).pdf](https://coronavirus-download.utah.gov/Health-provider/Final%20COVID19%20CSC%20Annex%20April%2015%202020%20(1).pdf)

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⁴ *Id.* at 7

⁵ *Id.*

⁶ *Id.* at 8

⁷ *Id.* at 7

The State's Guidance Lacks Processes for Requesting Reasonable Accommodations

- In addition to the substantive concerns about the way the policies included in the 2018 Guidelines and the Annex, we also have concerns related to the process that is available to modify them as required by the Americans with Disabilities Act (“ADA”). There is no formal process in these documents to request a reasonable accommodation.
- The Standards do not make reasonable accommodations to ensure that underlying disabilities, or other co-morbid conditions not associated with acute infection or short-term survivability, are not captured in the MSOFA scoring process or the Patient Prioritization Tool. Such accommodations may include increasing the priority tier thresholds for critical care, or specifically excluding underlying impairments where no compelling evidence exists that those conditions will impact short-term survivability as asserted by a similar complaint in Massachusetts.⁸ Both Massachusetts and Delaware have added specific language to their guidelines allowing for the modification of the SOFA based on a different baseline condition for many individuals with disabilities.⁹
- The Annex references the possibility of an appeal made on behalf of an individual (presumably one who has been denied some type of care) or their family, however it is unclear what criteria will determine whether an appeal is successful.¹⁰ There is no directive that any appeal should necessarily evaluate whether a request for accommodation has been made such as the type of modification to the MSOFA or Patient Prioritization Tool described above.¹¹
- There is similarly no guidance that personal medical equipment must remain with the individual to whom it belongs, or that interpretive services must be provided for patients requiring it for effective communication. The State should issue clear guidance on these points to ensure that all people with disabilities have access to information about their care.

We thank you for your time and effort to investigate our concerns. Should you have any additional questions, please do not hesitate to contact our office.

⁸ *Center for Public Representation's Letter to Governor Baker* (March 26, 2020), https://www.centerforpublicrep.org/wp-content/uploads/2020/03/3.26.20.ltr_rationing_of_care.pdf at 2.

⁹ *Massachusetts Crisis Standards of Care Planning Guidance for the Covid 19 Pandemic* (Revised April 20, 2020), https://www.centerforpublicrep.org/wp-content/uploads/2020/04/CSC-revised-4-20-2020_final.pdf at 10; *Delaware Crisis Standards of Care Concept of Operations* (Revised April 29, 2020), <https://www.centerforpublicrep.org/wp-content/uploads/2020/05/DE-CSC-ConOps-FInal-4-29-20.pdf> at 17.

¹⁰ *Utah Crisis Standards* at 8.

¹¹ *Id.* at 7.

Sincerely,



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