July 10, 2020

Governor Little  
State Capitol  
PO Box 83720  
Boise, ID 83720  

Also sent via email: governor@gov.idaho.gov

Dear Governor Little:

On April 14, 2020, we wrote your office concerning medical rationing standards in Idaho. At that time, Idaho did not have crisis standards of care, and we hoped to foreclose the need for HHS OCR complaints regarding discriminatory standards of care by alerting your office to complaints being filed around the country.

In our April 14, 2020 letter, we laid out five principles compiled by the Consortium for Citizens with Disabilities which are drawn from the ADA and other federal disability discrimination laws. These principles are as follows:

1. That the ADA and Section 504 require government decisions regarding the allocation of treatment/life-saving resources to be made based on individualized determinations, using current objective medical evidence, not generalized assumptions about a person’s disability;

2. That the ADA and Section 504 prohibit treatment allocation decisions based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living;

3. That the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person with a disability has a lower prospect of survival;

4. That the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person’s disability will require the use of greater treatment resources;

5. That a person is “qualified” for purposes of receiving COVID-19 treatment if they can benefit from the treatment (that is, can recover) and the treatment is not contraindicated.
We requested a response to that letter by April 17, 2020, but did not receive one. After having reviewed Idaho’s newly implemented Crisis Standards of Care (CSC) and Patient Care Strategies for Scarce Resource Situations (Patient Care Strategies), it is clear that Idaho has not thoroughly considered its legal obligations to individuals with disabilities under the Americans with Disabilities Act Titles II and III.

While DRI understands that triage policies are necessary in times of natural disasters or pandemics, federal laws including Section 1557 of the Affordable Care Act (ACA), Section 504 of the Rehabilitation Act (Section 504), and the Americans with Disabilities Act (ADA) require that these policies set neutral decision-making rules based on the individual medical condition of the patient. We acknowledge that the developers of the Crisis Standards of Care, the Idaho Department of Health and Welfare and SIDMAC, included a provision assuring that individuals with disabilities, access and functional care needs “will receive fair and equitable access to healthcare services both for disaster-related illness or injury as well as pre-existing conditions.” However, in our review of the Standards of Care, we noticed a number of provisions which will unlawfully discriminate against individuals with disabilities. In fact, it is our position that the Strategies as currently drafted will have the unintended consequence of disproportionately disqualifying individuals with disabilities for ventilator access, life-saving renal therapy, and other intensive treatments simply because they have underlying conditions which may intensify symptoms and slow recovery. CSC, 31.

For instance, the Patient Care Strategies set a discriminatory tone by relying on “restrict[ing] or prioritize[ing] use of resources to those patients with a better prognosis or greater need.” See Summary Card at page iii. Long-term survival projections are significantly less certain than the assessment of short-term survivability. Indeed, the Department acknowledges this on page 29 of Patient Care Strategies when it notes that, “predicted prognosis does not equate with actual outcome in many cases.” Nevertheless, Idaho’s entire triage policy is built around metrics that prioritize long-term survivability over a patient’s immediate response to treatment of an acute healthcare crisis.

Of particular concern is the use of the Glasgow Coma Score (GCS) and the Sequential Organ Failure Assessment (SOFA) in steps one and two of the Mechanical Ventilation for Adults beginning on page 4 of Patient Care Strategies. The Department states that the ethical goal of the allocation framework is to “focus...on saving the most lives and life years, in the context of ensuring meaningful access for all patients, ensuring individualized patient assessments, and diminishing the negative effects of social inequalities that lessen some patients’ long-term life expectancy.” *Id.* Unfortunately, use of the GSC and the SOFA score often negatively impacts individuals with disabilities due to the varying ways in which their comorbidities skew these scores.

You should note that American Academy of Developmental Medicine and Dentistry released a Ventilators & COVID-19 Policy Statement (AADMD Statement) in April of this year that outlines the discriminatory impact of GSC and SOFA scores for individuals with developmental disabilities in particular. That statement is enclosed with this letter. The GSC is typically meant to be used to assess acutely altered mental status. *Patient Care Strategies*, 6, and *AADMD Statement*, 2. For people with intellectual or developmental disabilities, characteristics of neurodevelopmental disorders, such as seizure disorders or sensory differences or communication difficulty may be an individual’s baseline and do not necessarily reflect acute brain trauma or indicate one’s immune response to COVID-19. *AADMD Statement*, 2. However, such disorders would trigger problematic GCS scores which would then negatively influence the SOFA score.
The AADMD also highlighted two issues that could apply to the use of SOFA scores on individuals with disabilities more broadly: 1. “Given the combination of characteristics inherent in the population of people with IDD, it would be possible to use the ‘objective’ data surrounding the SOFA score to predict a significantly higher mortality risk than is really the case;” and 2. “Because of the known risk of bias, diagnostic overshadowing, and lack of experience and training in the medical field in general with respect to patients with IDD, [there are] serious concerns about the current use of the SOFA as fair or objective means by which to allocate scarce medical resources.” AADMD Statement at 2 and 3.

The above issues are also concerning in light of the ethical framework’s stated goal of saving, “the most lives and life years…” Patient Care Strategies at 4. In step three of the Mechanical Ventilation for Adults, the Department further risks cutting off individuals with disabilities by assigning additional points to the existence of comorbidities which would shorten a patient’s long-term survivability. Then in step four, Patient Care Strategies recommends using the age of patients to break ties in resource allocation by noting that older patients are lower priority than younger ones. Just as patients with IDD may have a baseline that is different than someone without IDD, so too patients with other disabilities may have comorbidities that are their baseline but do not indicate acute status necessitating higher SOFA scores and lower prioritization when deciding where to allocate life-saving ventilation treatments. Additionally, older individuals generally have other health problems or disabilities that would similarly skew their eligibility for care.

The Office for Civil Rights recently intervened in Tennessee where use of the SOFA score, comorbidities and use of long-term survivability to determine prioritization of ventilation treatment drew the attention of disability rights advocates. OCR offered technical assistance to Tennessee resulting in a revision of its CSCs. A copy of Tennessee’s new guidelines and the press release containing OCR’s resolution is enclosed with this letter. Tennessee must make reasonable modifications to SOFA criteria so that they do not result in individuals with disabilities receiving deceptively high scores. Tennessee also had to remove provisions that relied on long-term survivability. The new standards give priority to those who would survive the immediate, acute healthcare situation rather than those who would ostensibly survive the longest.

OCR also had to intervene for chronic ventilator users in Tennessee. Under its initial guidelines, Tennessee was re-allocating chronic ventilator users’ personal ventilators to other patients deemed higher priority. Similarly, Idaho’s CSC guidelines for chronic ventilator users note that if community dwelling patients with their own ventilators, “need new or hospital-grade ventilators, they would enter the triage algorithm like any other patient,” and that chronic ventilator users who reside in nursing facilities are also at risk of losing their personal ventilators because they, “typically need to be transitioned to a hospital-based ventilator in the event of hospitalization…[and] risk losing their ventilator access on arrival to the hospital, as they would be triaged for ventilator access like any other patient.” Id. at 9. There is no mention in either of these provisions as to whether these patients are allowed to keep their home equipment or whether it will be taken from them and re-allocated in the event of CSC.

Under the Idaho’s current use of GCS, SOFA, comorbidities and age to prioritize who receives access to mechanical ventilation, such treatment of chronic ventilator users will almost certainly lead to imminent death for these patients—many of whom are aged and disabled. As in Tennessee, Idaho must immediately include language explicitly stating that chronic ventilators will not be deprived of their personal ventilators upon admission to the hospital.
Additionally, there are two other concerning elements in Idaho’s CSC: using the same triage policies above if renal replacement therapy becomes a scarce resource and leaving the use of extra-corporeal membrane oxygenation (ECMO) to the discretion of practitioners. Patient Care Strategies at 17 and 19. As stated above, using the current triage and resource re-allocation priorities to determine who receives renal replacement therapy is discriminatory and must be updated so that reasonable accommodations can be made for comorbidities that are already a part of someone’s baseline functioning and so that long-term survivability are no longer factors in determining who receives care.

As to the use of ECMO, the standards unfortunately discourage the use of ECMO for infants is because of its “very high staffing and supply needs.” Resource intensity and duration of need should not be factors that practitioners can consider when determining how to allocate scarce medical resources, as these factors would also have a discriminatory impact on infants with disabilities and could deprive them of the chance to experience life at all.

It is imperative that Idaho update their existing CSC to include reasonable modifications to GCS and SOFA scores, explicit language protecting chronic ventilator users from the loss of their personal ventilators, and remove any language suggesting that resource intensity and duration of need should influence treatment decisions. The lives of Idahoans with disabilities – encompassing tens of thousands of Idaho citizens – are inherently valuable and under the law, they have an equal right to health care treatment. DRI would like to engage with the with your office, the Idaho Department of Health and Welfare and SIDMAC regarding these standards. However – with Idaho’s COVID infection rates continuing to skyrocket during the month of July – time is of the essence. Therefore, please be aware that if we do not receive a response to this letter by Friday, July 24, we will be forced to file a complaint with OCR.

Sincerely,

Lessie R. Brown
Staff Attorney

LRB/ds

Enc.: Guidance for the Ethical Allocation of Scarce Resources
OCR Resolves Complaint with Tennessee After it Revises its Triage Plans to Protect Against Disability Discrimination
Ventilator Policy Statement - Addendum

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