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March 31, 2020  
By Electronic Mail

Governor Kevin Stitt  
Secretary of Health and Mental Health Jerome Loughridge  
Lt. Governor Matt Pinnell  
Attorney General Mike Hunter  
Senate President Pro Tem Greg Treat  
Speaker of the House Charles McCall

Dear Governor Stitt and other distinguished State officials:

We write on a matter of urgency regarding non-discriminatory access to life-saving medical care for people with disabilities, including those with psychiatric, developmental, intellectual and physical conditions who contract COVID-19. While the impacts of the current COVID-19 crisis are felt throughout the State in a myriad of ways, there is no greater concern than access to life saving care, and the ability of our health care system to respond to the anticipated need for intensive care and ventilator access for thousands of residents. We are writing you to express our concerns with the Oklahoma State Department of Health's (OSDH) draft document entitled "Hospital Crisis Standards of Care". This document which is drafted to provide rules for Oklahoma hospitals on medical care contains discriminatory restrictions on medical care for people with disabilities in Oklahoma.

People with disabilities are, and will be, at high risk of contracting COVID-19, particularly those who are in congregate residential programs, state-operated institutional settings, prisons and jails, and long term care facilities. We recognize and appreciate that the State is already making efforts to protect these residents' safety and their ability to access medically necessary services.

At this moment, it is also critical that state officials take specific steps to ensure that life-saving care is not illegally withheld from disabled citizens, including aging adults with comorbid conditions, due to discriminatory resource allocation or altered standards of care.

All state and private entities overseeing the delivery of life-saving medical interventions must make treatment decisions consistent with the non-discrimination requirements of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. Yet, around the country national and state advocacy groups are confronting outdated and discriminatory policies on emergency resource allocation in which

individuals with specific disabilities or functional impairments can be denied access to, or subjected to the removal of, medically necessary ventilators.<sup>1</sup>

In response to such policies, the National Council on Disability (NCD)<sup>2</sup> and the Consortium for Citizens with Disabilities (CCD)<sup>3</sup> have proposed important principles for the delivery of care. In keeping with those national organizations, and consistent with our respective organizations' missions, we urge the State to immediately adopt and disseminate mandatory statewide guidelines which clarify the following:

- 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; and
- 5) that a person is "qualified" for purposes of receiving COVID-19 treatment if he or she can benefit from the treatment (that is, can recover) and the treatment is not contraindicated.<sup>4</sup>

In addition, HSS Office for Civil Rights just released a new guidance bulletin on Saturday, March 28, 2020<sup>5</sup>, which further emphasizes the need for clearly defined, non-discriminatory procedures for dealing with the potential and anticipated shortages of critical medical supplies amid the Covid-19 pandemic. We urge the State to consider and follow this guidance and would point particularly to the following language from the bulletin:

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<sup>1</sup> Office of Civil Rights complaints filed against the States of Washington and Alabama can be found at <https://www.centerforpublicrep.org/news/cpr-and-partners-file-second-complaint-regarding-illegal-disability-discrimination-in-treatment-rationing-during-covid-19-pandemic/>

<sup>2</sup> See, Letter of National Council to Roger Severino, Director, Office for Civil Rights, U.S. Department of Health & Human Services, March 18, 2020, available at <https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr>

<sup>3</sup> CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

<sup>4</sup> See, Consortium of Citizens with Disabilities, letter to Secretaries of EOHHS and the Office of Civil Rights, March 20, 2020, available at <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>

<sup>5</sup> See, OCR Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19), March 28, 2020, available at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

“The Office for Civil Rights enforces Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act which prohibit discrimination on the basis of disability in HHS funded health programs or activities. These laws, like other civil rights statutes OCR enforces, remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.”

The Oklahoma State Department of Health (OSDH) guidance for medical treatment draft document entitled “Hospital Crisis Standards of Care” does not directly address the resolution of critical questions concerning how allocation of resources for people with disabilities will occur at a time when demand exceeds system capacity. Nor do they provide specific guidance to private hospitals and ethics committees who will be on the front lines of thousands of individual treatment decisions. These guidelines simply direct that limited medical resources will be allocated in a way that maximizes the number of lives saved. This approach to maximization is often informed by an assessment of “comparative ability to benefit” from treatment, which then leads to conscious or unconscious discrimination based on disability.<sup>6</sup>

Oklahoma makes use of overly broad diagnostic restrictions that are not well grounded in research and evidence, but may under this allocation scheme have the effect of depriving people with disabilities from access to care. For example, under the OSDH documents, seemingly arbitrary and discriminatory guidance is provided regarding the re-allocation of ventilators. Page 12 of OSDH’s “Hospital Crisis Standards of Care” document, recommends that one major factor to consider is a patient’s injury or epidemiologic factors and underlying diseases. Examples given of underlying disease that serve as a predictor of poor short term survival include: patients who have pre-existing health conditions such as lung disease that already requires daily oxygen and/or ventilation assistance that would certainly continue to require such intervention beyond the 7-day cut-off listed in the document; and cystic fibrosis, a condition that with proper treatment and management can be consistent with a typical lifespan or nearly so.

These types of protocols do not take into account the fact that what constitutes long duration may differ from patient to patient depending upon the extent of scarcity of resources and what other people need (i.e. what if all other patients in the ICU are also of long duration?). Without some provision to indicate that reasonable modifications must be made to the protocols for people with underlying disabilities, subjecting individuals who need the use of a ventilator to

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<sup>6</sup> May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing, Samuel R. Bagenstos, University of Michigan Law School, pp. 8-10, March 24, 2020, available at [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3559926](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3559926). An article published this week in the New England Journal of Medicine applies this rationale even to removing the existing use of a ventilator from one person, to provide it to another, with the aim of “maximizing benefits.” <https://www.nejm.org/doi/full/10.1056/NEJMs2005114?query=RP> This reasoning could be used to justify the repossession of ventilators currently being used by persons with disabilities for conditions that began long before COVID-19, for example ALS patients, and evokes long-repudiated theories of eugenics.

a 7-day duration of need limitation and then making them subject to reallocation is discriminatory. Likewise, there needs to be some clear guidance concerning reasonable modifications to decisions about re-allocation of critical care or ventilators in order to allow more time for patients to move from “stable” to “improving”.

What is needed is a set of mandatory principles like those listed above by the National Council on Disability, prohibiting discrimination and requiring the application of individualized and objective medical standards that deny or remove care only when continued treatment would be futile. Without the creation of a statewide policy, and a meaningful appeal process, the exercise of medical discretion across the State will be largely unchecked, unguided, and subject to wide variation. The unavoidable result will be highly subjective decision-making, needlessly placing even greater responsibility and stress on treating professionals.

Failure to act also presents the unacceptable risk that misplaced societal views about the relative quality or value of the lives of people with disabilities will result in their denial of life-saving treatment.

We are on the precipice of a statewide crisis in access to care, as the Governor has so aptly pointed out in recent press briefings. We applaud the strategic steps being taken to avert a crisis in managing both the rates of COVID-19 infection and the comprehensiveness of the State’s response. Oklahoma has an opportunity to be a national leader on these issues, by acting to establish equitable, democratic and nondiscriminatory standards of care before scarcity begins driving medical decisions across the State.

We stand ready to assist in these efforts, and can quickly bring to bear a range of local and national resources and expertise, including emerging best practices, to support the Governor, the COVID-19 command center, and the Oklahoma State Department of Health. At a minimum, we ask that you confirm your receipt of this letter and make clear how the State intends to address the disability community’s concerns regarding discriminatory rationing of care.

Thank you in advance for your consideration of this most important issue, and for your commitment to Oklahoma’s citizens with disabilities.

Sincerely,



Melissa Sublett,  
Executive Director



Brian S. Wilkerson,  
Legal Director