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April 21, 2020

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

Re: Complaint of the Oklahoma Disability Law Center, the Center for Learning and Leadership, the Oklahoma Developmental Disabilities Council, Progressive Independence, Oklahoma People First, Chandler DeBolt, Cassie Garrett, Joshua Miller, and Conner McDougall

Dear Mr. Severino:

We write to ensure non-discriminatory access to life-saving medical care for Oklahoma residents with disabilities across the lifespan, including persons with psychiatric, developmental, intellectual and physical disabilities, and older adults with co-morbid medical conditions, who contract COVID-19.

We are filing this Complaint challenging Oklahoma's recently issued standards on health care rationing, entitled Hospital Crisis Standards of Care: Resource Reference Cards ("Standards") (attached as Exhibit A). These standards will jeopardize the lives of people with disabilities, older adults and others with co-morbid conditions in violation of Title II of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (RA), Section 1557 of the Patient Protection and Affordable Care Act (ACA), and the Age Discrimination Act of 1975.

The Standards' triage scoring system penalizes patients with "life-limiting" and "major co-morbidities," regardless of how those co-morbidities impact the person's ability to benefit from COVID-19 treatment. The Standards also deny access to life-saving treatment based upon disability and age, deprioritizing individuals believed to have a poorer longer-term prognosis, with a goal of prioritizing individuals "who are yet to experience all of life's stages."¹ Finally, these Standards fail to require the provision of reasonable modifications to the triage process, as well as hospital communication and visitation policies, when necessary to accommodate an individual's disability. As a result, the Standards discriminate against persons with disabilities and older adults in violation of federal law.

¹ The discriminatory triage criteria are on Page 15 of the Standards, in a section entitled "Mechanical Ventilation/External Strategies for Scarce Resource Situations."

• *A system of protection and advocacy for persons with physical and mental disabilities* •

Oklahoma is only days away from an anticipated peak in COVID-19 transmission.² At that point the demand for care may exceed capacity, prompting heartbreaking decisions regarding the allocation of medical resources. While we understand that public officials and health care institutions are faced with the unenviable prospect of having to make difficult choices about how to allocate care, it is critical that OCR take immediate steps to ensure that life-saving care is not illegally withheld from disabled citizens, older adults, and others with co-morbid conditions, due to discriminatory triage criteria.

For this reason, we request a finding by your Office that triage factors which deny life-saving treatment to individuals based on underlying co-morbidities and long-term prognosis and age, must be eliminated from the Standards in order to comply with federal law.

Complainants

Oklahoma Disability Law Center (ODLC) is the federally funded protection and advocacy system for individuals with disabilities in the state of Oklahoma. Our office is mandated to protect the legal and civil rights of Oklahomans with disabilities. Our mission and legal advocacy has never been more important than in the face of the current Covid-19 pandemic, as we continue to monitor the emerging challenges faced by our citizens living with disabilities and the state's response to this public health emergency.

The Center for Learning and Leadership (CLL) is Oklahoma's federally designated University Center for Excellence in Developmental Disabilities (UCEDD). Our vision refers to "all" people and our mission refers to "partners." We believe in the value of people, diversity, inclusion, and participation; "All" means all. Without all of us, as a community, we are less than we could be. We believe that every person brings unique gifts to the world. Our vision is, "All people with disabilities and their families are valued participants in community life." Our mission includes partnering to make a positive difference in the lives of people with disabilities and their families through learning and leadership. The CLL/UCEDD vision and mission addresses four overarching goals: 1) Delivering Pre-Service & Continuing Education, including educating students and professionals in disability-related disciplines; 2) Providing community-based services, training, and technical assistance; 3) Conducting research and advocacy: Conducting community-based research and evaluation and providing best practice information and advocacy on issues important to people with disabilities and their families; and 4) Dissemination: Provide evidence-based information about disability-related topics.

The Developmental Disabilities Council of Oklahoma (DDCO) advocates for the rights of people with intellectual and developmental disabilities to be included in full and enviable lives in their communities. The mission of the DDOC is to lead and advocate for systems change in the field of developmental disabilities, leverage collaborations and partnerships toward improved

² OSDH Releases COVID-19 Modeling for Oklahoma, Estimates April 21 Peak available at <https://coronavirus.health.ok.gov/articles/osdh-releases-covid-19-modeling-oklahoma-estimates-april-21-peak>.

services and supports for Oklahomans with developmental disabilities, and promote positive perceptions and attitudes toward people with developmental disabilities.

Progressive Independence is a federally funded Center for Independent Living (CIL) that provides independent living services to all Oklahomans with a disability central Oklahoma. Their mission is to encourage and facilitate self-sufficient, independent lifestyles and to enhance the quality of life for individuals with disabilities in central Oklahoma.

Oklahoma People First, Inc (OPF) is Oklahoma's statewide Self Advocacy Organization for individuals with developmental and intellectual disabilities. The mission of OPF is to promote equality for people with disabilities; assist people with disabilities to speak for themselves; provide education for people in our communities; educate ourselves on disability issues; and gain public support for disability issues.

In addition to these organizations, this Complaint is brought by the following individuals:

Chandler DeBolt is a 24-year-old man who has cerebral palsy, secondary to a heart condition. Chandler is non-verbal, non-ambulatory, has scoliosis, diminished lung capacity, has an internal baclofen pump, is fed by a g-j-tube, and requires oxygen at night. Because of these conditions he is at higher risk of developing respiratory issues. When Chandler has had planned surgery, his scoliosis has impeded his airway making intubation difficult. Before COVID-19, Chandler received a few hours of private duty nursing care in his home. Since mid-March, Chandler's mother has been the sole provider of his care in order to limit the potential infection carried into the home. Chandler's condition is medically fragile and he is at risk of being perceived as someone whose life has diminished value. Chandler's parents are worried about what will happen to him if he is admitted to hospital during the COVID-19 crisis especially given the State's Crisis Standards. Chandler and his family want him to be treated the same as everyone else and want to make sure that other people with disabilities are also treated the same.

Cassie Garrett is a 34-year-old woman with Turner Syndrome, a chromosomal condition ascribing females with common features, physical traits and multiple medical conditions caused by the complete or partial absence of the second sex chromosome. This results in a lack of all hormones which impacts her mentally, emotionally and physically in numerous ways. Due to the number of times she has been intubated over a series of hospital stays, she is now unable to speak more than whispering a few words here and there. As a result, she cannot be heard over the nurse call system. She is also hearing impaired. Since the nurses all have masks on now due to COVID-19, she cannot read their lips to aid in her understanding. As a result of Turner Syndrome, she has many physical anomalies that require adjustments to be made in the way medical care is typically provided. For example, she fluid overloads very quickly (exacerbating pneumonia). She has very narrow, leaky vessels, so when she fluid overloads, she has to be given a special medication to pull the fluid back into her vessels. Her J tube and G tube for feeding and medication must be handled differently than a typical patient. Some of her veins typically used for central lines cannot be used because they do not travel to the places they should. She has an extremely poor short-term memory which has proven detrimental as she is unable to remember the unique needs and specific approaches that need to be communicated to medical staff due to her multiple disabilities. It is crucial people with disabilities be given special

accommodations like having an advocate or family member with them so their voice can be heard just the same as any other patient.

Joshua Miller is a 22-year-old male who is diagnosed with Agenesis of the Corpus Callosum, Autism, Tourette's Syndrome, Generalized Anxiety Disorder, auto-immune diseases and is visually impaired. Joshua also has developmental delays in all areas. His functional/developmental age is 6 years old. Joshua needs constant care throughout the day. He has extreme anxiety in new situations and often has meltdowns. He was born with a variety of congenital anomalies. One example is his constricted airway which puts him at high risk for developing complications with any throat or respiratory infection. Because of these conditions, he is at higher risk of developing more severe respiratory issues. When Joshua gets sick, it is a major event. He needs constant reassurance and explanations for what is happening. He also needs a caregiver who can use individualized and appropriate communication methods and tools to keep him calm and stable in a new and scary situation. Josh is at risk of being perceived as someone whose life has diminished value. His parents worry about what will happen if he is admitted to the hospital during the COVID-19 crisis, especially given the State's Crisis Standards. He deserves fair and equal treatment in a crisis situation. Fair, in this case, means getting what an individual needs to have the best chance for survival. A parent/caregiver must be with him at all times.

Conner McDougall is 15-year-old male. Conner was in a car accident when he was 20 months old that left him with a spinal cord injury at C 1,2, and 3. Due to a high level of spinal cord injury he requires a ventilator to help him breath 24 hours a day. Conner is at risk of being perceived as someone whose life has diminished value. Conner's mother and guardian is extremely worried about what will happen to him if he is admitted to hospital during the COVID-19 crisis especially given the State's Crisis Standards. He wants to be treated the same as everyone else and wants to make sure that other disabled people are also treated the same.

This Complaint follows similar actions filed with the Office of Civil Rights against state crisis standards in Washington, Alabama, Tennessee, Utah, Kansas, New York and Pennsylvania, and incorporates by reference the legal arguments set forth in the Washington complaint.³

Oklahoma Hospital Crisis Standards of Care

A. Background

On March 31, 2020, ODLIC wrote to Governor Kevin Stitt asking that state officials take specific steps to ensure that life-saving care is not illegally withheld from disabled residents and older adults, including individuals with co-morbid conditions, due to discriminatory resource allocation or altered standards of care. ODLIC urged the Governor to immediately adopt and disseminate mandatory statewide guidelines based on principles outlined by the National Council

³ These OCR complaints are available at <https://www.centerforpublicrep.org/covid-19-medical-rationing/> [This analysis incorporates the legal analysis of the Center for Public Representation and others concerning the Massachusetts Crisis Standards of Care.](#)

on Disability (NCD)⁴ and the Consortium for Citizens with Disabilities (CCD).⁵ ODLC further advised the Governor and his Administration of your Office’s March 28, 2020 Bulletin, and the federal government’s directive that civil rights laws prohibiting discrimination on the basis of disability in HHS funded health programs or activities “remain in effect,” including as they apply to the delivery of lifesaving care and treatment during the COVID-19 outbreak.⁶

On April 3, 2020, ODLC was invited to attend a conference call with a representative of the Oklahoma State Department of Health (OSDH) and a representative from the Governor’s office. On this call, ODLC learned for the first time that a small group of physicians, government officials and other health care workers, had met over the previous several days to develop Crisis Standards of Care for Oklahoma, without input from the disability community, advocates or older adults. The Standards were issued on April 10, 2020, and are the subject of this Complaint.

Additionally, the Standards provide no guidance on hospital visitation policies, nor has the State issued any statewide protocols covering this issue. Currently, Oklahoma hospitals are each developing their own visitor policies that, in many cases, exclude guardians and caregivers of people with disabilities from participation in their care. On April 13, 2020, ODLC sent a letter to the Governor and OSDH imploring them to immediately adopt a statewide policy on hospital visitation during the Covid-19 emergency that includes exceptions for people with disabilities who may require a support person to stay with them during emergency room visits and hospitalizations. ODLC reminded the Governor and OSDH that individuals with disabilities who need communication or behavioral supports in hospital situations retain their rights to reasonable accommodations under federal law, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act (ACA), even in a pandemic. To date, there has been no response from the Governor or the OSDH.

B. The Oklahoma Standards’ Triage Assessment Process

The Standards enumerate 6 “General Core Strategies” to which each health care institution will adhere. Standards at 4. Yet, neither the OCR Bulletin, nor any applicable federal civil rights laws, are mentioned anywhere in the Standards, other than a short paragraph at the end of the Table of Contents. There are no required safeguards against unconscious bias, or guidance on

⁴ See, Letter of the National Council on Disability to the U.S. Department of Health & Human Services, Office for Civil Rights, March 18, 2020, available at <https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr>.

⁵ See, Letter of the Consortium of Citizens with Disabilities, to the U.S. Department of Health & Human Services, Office for Civil Rights, March 20, 2020, available at <http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf>.

⁶ See, <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.

how to avoid discriminatory application of triage principles against persons with disabilities and others with underlying, co-morbid medical conditions.⁷

The Standards' allocation framework is based on two considerations: 1) saving the most lives; and 2) prioritizing "life-cycle and instrumental value/reciprocity principles". *Id.* at 15. Patients who do not have serious co-morbid illness are given priority over those who have illnesses that limit their life expectancy. *Id.* at 14. The allocation process for ventilation calls for hospitals to "calculate a total score using the multi-principle allocation framework (short-term + long-term prognosis score "[range 1-8]." *Id.* Using this numerical score, each patient is placed in a priority group. The higher a patient's score, the less likely they are to receive lifesaving care. *Id.*

Priority scoring for patients over is outlined as using the Sequential Organ Failure Assessment (SOFA) score to characterize patients' prognosis for hospital survival. The presence of significant life-limiting comorbid conditions is used to characterize patients' longer-term prognosis. Points are assigned for SOFA score category and the presence of comorbid conditions, and points for severely life-limiting comorbidities. These points are then added together to produce a total priority score, which ranges from 1 to 8. Lower scores indicate higher likelihood to benefit from critical care; priority will be given to those with lower scores. Standards at 13-14.

The presence of "major" and "severely life-limiting" co-morbid conditions are used to predict "prognosis for long-term survival." *Id.* Patients' expected longevity or "prognosis for long-term survival (medical assessment of co-morbid conditions)" can be a deciding factor in whether or not they are prioritized for ventilation. *Id.* Finally, if the scores of two individuals are identical and only one treatment intervention is available, the life-cycle and instrumental value/reciprocity principles will be used as "tie-breaker". These decision-making tools prioritize care for "individuals who are yet to experience all of life's stages" and individuals who play a key role "in protecting public health and maintaining societal functioning". *Id.* at 15. Clearly, using this type of criteria as a tool for deciding who should receive life-sustaining care and who should not, places individuals with disabilities and older adults at a huge disadvantage and is discriminatory, in violation of federal law.

Oklahoma Standards Violate Federal Law

A. Legal Standards

Title II of the ADA prohibits public entities (such as state and local governments) from excluding people with disabilities from their programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Implementing regulations promulgated by the United States

⁷ The Standards do include a list of factors which are not to be considered in the allocation of scarce medical resources, including but not limited to race/ethnicity, gender, sexual orientation, disability, perceptions of quality of life, insurance status, or broad social worth. Standards at 15. However, the triage criteria make it impossible to be faithful to these principles.

Department of Justice (DOJ) define unlawful discrimination under Title II to include, *inter alia*: using eligibility criteria that screen out or tend to screen out individuals with disabilities, failing to make reasonable modifications to policies and practices necessary to avoid discrimination, and perpetuating or aiding discrimination by others. 28 C.F.R. §§ 35.130(b)(1)-(3), 35.130(b)(7)-(8). Moreover, DOJ has explicitly instructed that Title II of the ADA applies to emergency preparedness efforts of state and local governments, writing:

One of the primary responsibilities of state and local governments is to protect residents and visitors from harm, including assistance in preparing for, responding to, and recovering from emergencies and disasters. State and local governments must comply with Title II of the ADA in the emergency- and disaster-related programs, services, and activities they provide.⁸

Section 504 of the Rehabilitation Act similarly bans disability discrimination by recipients of federal financial assistance, including Oklahoma's state agencies and most hospitals and health care providers. 29 U.S.C. § 794(a). The breadth of Section 504's prohibition on disability discrimination is co-extensive with that of the ADA. *See, e.g., Frame v. City of Arlington*, 657 F.3d 215, 223 (5th Cir. 2011) ("The ADA and the Rehabilitation Act are generally interpreted *in pari materia*.").

Section 1557 of the ACA provides that no health program or activity that receives federal funds may exclude from participation, deny the benefits of their programs, services or activities, or otherwise discriminate against a person protected Section 504 of the Rehabilitation Act, 42 U.S.C. § 18116; 45 C.F.R. §§ 92.101(a), 92.101(b)(2)(i). This includes an obligation to make reasonable modifications in policies, practices, and procedures necessary to avoid discrimination. 45 C.F.R. § 92.205.

The Age Discrimination Act, also incorporated by Section 1557, prohibits discrimination on the basis of age in programs or activities that receive federal financial assistance. 42 U.S.C. §§ 6101-6107. No person in the United States shall, on the basis of age, be excluded from participation, in be denied the benefits of, or be subjected to discrimination under, such a program. 34 C.F.R. § 110.10(a).

B. Penalizing individuals with underlying co-morbid conditions, regardless of the likelihood of survival from COVID-19, short term survivability or ability to benefit from treatment, constitutes discrimination on the basis of disability and age.

No patient should be disqualified from life-saving treatment solely because of underlying co-morbid conditions. Oklahoma's reliance on these criteria dramatically increases the likelihood that individuals with disabilities and older adults will be denied lifesaving care based on discriminatory assumptions about their quality of life or structural inequities that may impact overall life expectancy. The Standards factor co-morbidities into the triage process in two

⁸ *See*, DOJ, Emergency Management Under Title II of the Americans with Disabilities Act at 1 (July 26, 2007), available at <https://www.ada.gov/pcatoolkit/chap7emergencymgmt.htm>.

distinct ways: 1) in calculating the individualized SOFA score; and 2) by adding additional “points” for life limiting and severe co-morbid conditions.

1. The Sequential Organ Failure Assessment (SOFA)

The SOFA is intended to assess short term impairments arising out of an acute care episode and their impact on survivability to discharge.⁹ Even when based on individualized medical evidence, instruments like the SOFA may inappropriately penalize individuals with chronic, but stable underlying disabilities. For example, the Glasgow Coma Scale, a tool for measuring acute brain injury severity in the SOFA, adds points when a patient cannot articulate intelligible words, even if this condition is due to a pre-existing speech disability. Patients with pre-existing motor impairments are also disadvantaged by this measure which requires moving in response to verbal commands.

Triage teams must avoid penalizing individuals with chronic but stable underlying conditions, including individuals with disabilities and older adults, when calculating SOFA scores. Baseline levels of impairment prior to the acute care episode should not increase SOFA scores unless objective medical evidence, interpreted by a medical professional with expertise necessary to exercise professional judgment under usual standards of care, demonstrates that those conditions directly impact an individual’s short-term survivability with treatment.

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 SOFA scoring process. 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.

Because Oklahoma allows the SOFA to lower an individual’s priority for lifesaving care based solely on the presence of chronic, but stable, underlying conditions like diabetes, Alzheimer’s disease, chronic kidney disease, COPD, developmental disability, brain injury, or speech and motor impairments, it violates federal anti-discrimination laws and directives from the Office of Civil Rights.

2. Penalizing patients with “life-limiting” co-morbidities

In addition to the SOFA score, patients awaiting ventilation receive additional points based on the presence of co-morbid conditions. Standards at 13-14. The Standards make clear that patients who do not have serious co-morbid illness are given priority over those who have illnesses that limit their life expectancy. *Id.*

It is highly likely that individuals with disabilities will be perceived as having “life-limiting” or “major” co-morbidities, based on discriminatory assumptions about their conditions, or

⁹ See, ClinCalc.com, SOFA Calculator: Sequential Organ Failure Assessment (SOFA) Severity of Illness Score for Hospital Mortality, available at <https://clincalc.com/IcuMortality/SOFA.aspx>.

misperceptions about the value and utility of their lives.¹⁰ Such conduct is wholly at odds with federal non-discrimination laws as they de-prioritize certain people based on their disability diagnosis. *See Wagner v. Fair Acres Geriatric Center*, 49 F.3d 1002, 1015 (3d Cir. 1995) (holding that nursing home could violate Section 504 of the RA and Title II of the ADA by excluding a person with Alzheimer’s disease who would require a higher level of care); *Lovell v. Chandler*, 303 F.3d 1039, 1053 (9th Cir. 2002) (holding that state’s exclusion of people who were blind or disabled from a new managed care program violated Section 504 and Title II of the ADA), *cert. denied*, 537 U.S. 1105 (2003). Your Office’s recent Bulletin also made clear that it is unlawful to make treatment decisions based on “judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities.”¹¹

The ADA and Rehabilitation Act bar the use of eligibility criteria that screen out or tend to screen out individuals with disabilities from access to services. *See, e.g.*, 42 U.S.C. § 12182(b)(2)(A)(i); 28 C.F.R. § 36.301 (ADA public accommodations); 28 C.F.R. § 35.130(b)(8) (ADA public entities). Patients with disabilities and older adults are more than likely to be screened out of high priority categories under the Standards, because they have conditions that will automatically add points to their score. This is true even if their underlying conditions are stable and have no impact on their ability to benefit from intensive care services, including ventilation.

Another core tenet of the ADA and Rehabilitation Act is that decisions by covered entities must not be based on myths, stereotypes, and unfounded assumptions about people with disabilities; rather, they must be based on individualized determinations using objective evidence. *See School Bd. of Nassau County v. Arline*, 480 U.S. 273, 284-85, 287 (1987). The use of co-morbid diagnoses in instances in which a person’s immediate-term survivability is not negatively impacted as a result of the diagnosis is directly contrary to this tenet.

State triage protocols cannot treat disabled patients as unqualified for lifesaving care when those disabilities do not affect their ability to benefit from the treatment sought. “Long standing and authoritative interpretations of the law bar the use of such circular techniques to insulate disability discrimination from legal challenge.”¹²

¹⁰ *See generally*, NAT’L COUNCIL ON DISABILITY, MEDICAL FUTILITY AND DISABILITY BIAS 29 (Nov. 20, 2019) (“Several studies have demonstrated that health care providers’ opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people. For example, one study found that only 17 percent of providers anticipated an average or better quality of life after a spinal cord injury (SCI) compared with 86 percent of the actual SCI comparison group. The same study found that only 18 percent of emergency care providers imagined that they would be glad to be alive after experiencing a spinal cord injury, in contrast to the 92 percent of actual SCI survivors.”) (footnotes omitted), available at https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf.

¹¹ *See*, n. 6, *supra*.

¹² Samuel R. Bagenstos, *May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing*, University of Michigan Law School, p.2, March 24, 2020, available at https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3559926.

C. *Lowering patients' priority for care based on underlying co-morbid conditions exacerbates underlying inequities in the health care system.*

Reliance on criteria like co-morbidity and projected longevity increase the likelihood that disabled individuals, and those more likely to have underlying chronic conditions, including older adults, will be denied lifesaving care. The Standards reinforce current and historical inequities in access to health care, and risk importing quality of life criteria or unconscious bias into the triage process. These inequities could not be highlighted more clearly than by the Standards' use of the life-cycle and instrumental value/reciprocity principles as criteria for allocating care. Similarly, attempts to predict and score patients based on long term prognosis will lead to inconsistent and subjective decision-making, higher rates of clinical error, and discriminatory allocation of care.

People with disabilities and older adults have long experienced discrimination in their access to medical and preventative health care.¹³ Over time, this discriminatory treatment leads to more co-morbid conditions and lower than average longevity. For instance, people with psychiatric disabilities are among those with lower life expectancies due to co-morbidities associated with years of antipsychotic medication and related side-effects, a history of segregation and substandard treatment, and marginalization in access to health care.¹⁴

Incarcerated persons, many of whom have co-morbid conditions, are also at significant risk of contracting COVID-19.¹⁵ Cases have already been reported in Oklahoma prisons and jails and

¹³ See, e.g., NAT'L COUNCIL ON DISABILITY, ORGAN TRANSPLANT DISCRIMINATION AGAINST PEOPLE WITH DISABILITIES (Sept. 25, 2019), available at https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf.

¹⁴ World Health Organization, Information Sheet: Premature death among persons with severe mental disorders (reporting 10-25 year life expectancy reduction) available at https://www.who.int/mental_health/management/info_sheet.pdf; Thomas Insel, Post by Former NIMH Director Thomas Insel: No Health Without Mental Health, Nat'l Instit. of Mental Health (September 6, 2011)(Citing studies that "Americans with major mental illness die 14 to 32 years earlier than the general population.") available at <https://www.nimh.nih.gov/about/directors/thomas-insel/blog/2011/no-health-without-mental-health.shtml>; M. De Hert, et al., Physical Illness in Patients with Severe Mental Disorders, 10 World Psychiatry 52 (2011) (people with SMI receive inadequate treatment by health care providers; "... stigmatization, discrimination, erroneous beliefs and negative attitudes associated with SMI will have to be eliminated to achieve parity in health care access and provision.") and/or N. Liu, et al., Excess Mortality in Persons with Severe Mental Disorders: A Multilevel Intervention Framework and Priorities for Clinical Practice, Policy and Research Agendas, 16 World Psychiatry 30 (2017) (Although persons with serious mental illness have two times as many health care contacts, they receive fewer physical check-ups and screenings, fewer prescriptions and less treatment for physical ailments than other patients.).

¹⁵ Emma Grey Ellis, Covid-19 Poses a Heightened Threat in Jails and Prisons, Wired (March 24, 2020) available at <https://www.wired.com/story/coronavirus-covid-19-jails-prisons/>.

the Governor has signed over 450 commutations in an effort to help reduce overcrowding during the Covid-19 pandemic.¹⁶

Finally, people with disabilities and older adults are at high risk of contracting COVID-19, particularly those who receive hand-on personal care, live in congregate residential programs, or are served in institutional settings, or long-term care facilities.¹⁷ These individuals also are at greater risk of requiring hospital level of care and, therefore, finding their access to treatment determined by discriminatory Standards.¹⁸

D. The Standards' goal of prioritizing "life-cycle and instrumental value/reciprocity principles" discriminates against individuals with disabilities and older adults.

Although the Standards do not categorically exclude patients based on diagnosis, they rely heavily on maximization of efficiency in allocating lifesaving resources, with the stated goal of saving individuals who are yet to experience all of life's stages and focuses on an individual's skills. Standards at 15. These principles – efficiency and prioritizing younger, societally productive individuals – discriminate against people with disabilities and other protected classes.

Importantly, the American College of Physicians has rejected the use of long-term prognosis or “number of life years,” instead recommending that hospitals make resource allocation decisions

based on patient need, prognosis (determined by objective scientific measures and informed clinical judgment) and effectiveness (i.e., the likelihood that the therapy will help the patient recover). Allocation of treatments must maximize the number of patients who will recover, not the number of “life-years,” which is inherently biased against the elderly and the disabled.¹⁹

¹⁶ Coronavirus in Oklahoma: Stitt signs over 450 commutations, reduces prison overcrowding during COVID-19 pandemic-available at <https://oklahoman.com/article/5659929/coronavirus-in-oklahoma-stitt-signs-over-450-commutations-reduces-prison-overcrowding-during-covid-19-pandemic>

Also see, Five Prison Staff, One Prisoner In Oklahoma Test Positive for COVID-19-available at <https://www.kosu.org/post/five-prison-staff-one-prisoner-oklahoma-test-positive-covid-19>

¹⁷ See, Coronavirus cases spread in nursing homes as facilities face ‘absolute devastation’ <https://www.readfrontier.org/stories/coronavirus-cases-surge-at-nursing-homes-as-workers-face-absolute-devastation/>, also Inside nursing homes, coronavirus brings isolation and 7,300 deaths; Outside, families yearn for news <https://abcnews.go.com/Health/inside-nursing-homes-coronavirus-brings-isolation-7300-deaths/story?id=70225836>

¹⁸ See, Oklahoma nursing homes impacted by COVID-19 <https://kfor.com/news/local/oklahoma-nursing-homes-impacted-by-covid-19/>, also see 63 People At Grove Nursing Home Test Positive For COVID-19 <https://www.newson6.com/story/42008006/63-people-at-grove-nursing-home-have-tested-positive-for-covid19>, also see Group home residents under quarantine following COVID-19 death https://www.normantranscript.com/news/group-home-residents-under-quarantine-following-covid--death/article_7b98026c-7292-11ea-872e-872b711eccdf.html

¹⁹ Available at <https://www.acponline.org/acp-newsroom/internists-say-prioritization-allocation-of-resources-must-not-result-in-discrimination>.

Even Dr. Douglas White, author of the much cited “Pittsburgh Model” for altered standards of care, has publicly rejected factoring long- term prognosis and overall life expectancy into the triage assessment process. Instead, Dr. White advocates for considering prognosis in the near term.²⁰

Additionally, the Standards use life-cycle and value/reciprocity categories to determine how lifesaving resources will be allocated between patients with the same triage score. This “tie-breaker” provision violates the Affordable Care Act’s anti-discrimination provisions, the Americans with Disabilities Act, as well as the Age Discrimination Act of 1975, which establishes that “no person ... shall, on the basis of age, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any program or activity receiving Federal financial assistance.” 42 U.S.C. § 6102.

Risks of error and unconscious bias may be even greater in high pressured triage decisions during this crisis. Medical innovations such as new pharmaceuticals, surgical techniques and other interventions can shift the long-term prognosis for many conditions.

New York State has charted a different course. Its ventilator guidelines eliminate any consideration of comorbidity or long-term prognosis.²¹ Instead, they assess “the short-term likelihood of survival of the acute medical episode,” and not “whether a patient may survive a given illness or disease in the long-term (e.g., years after the pandemic). By adopting this approach, every patient is held to a consistent standard. Triage decision-makers should not be influenced by subjective determinations of long-term survival, which may include biased personal values or quality of life opinions.”²²

E. Assessments of long-term prognosis based on “significant life limiting comorbidities” are prone to discriminatory assumptions, unconscious bias, and clinical error.

The proposed triage guidelines provide no objective, reliable, or consistent means of informing decisions on intermediate or long-term prognosis. Additionally, populations whose health and longevity are already negatively impacted by inequities in access to care (people with psychiatric disabilities; people with developmental disabilities; older individuals; incarcerated people) will

²⁰ This April 8, 2020 interview on WBUR is available at

<https://www.wbur.org/hereandnow/2020/04/08/hospitals-ethically-ration-ventilators>.

²¹ New York State Department of Health, “Ventilator Allocation Guidelines,” by the New York Taskforce on Life and the Law, November 2015, 34, available at

https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf.

²² Elios Rivera-Segarra, et. al., “That’s All Fake”: Health Professionals, Stigma and Physical Healthcare of People Living with Serious Mental Illness, 14 PloS One, 12, (2019) available at <https://doi.org/10.1371/journal.pone.0226401>.

be doubly harmed by these criteria, undermining the Standards' stated goals of equity, transparency and fairness in the rationing process.²³

The Standards utilize criteria that will lead to discriminatory assumptions or unconscious bias in the provision of lifesaving care.²⁴ Further, they fail to include safeguards against such influences in the decision-making process. Specifically, incorporating co-morbidities that do not reduce a patient's short-term survival prospects into the triage assessment creates a substantial risk that quality of life and other subjective value judgments will also be improperly incorporated into the process reducing the likelihood persons with disabilities and chronic health conditions will receive medically indicated care.²⁵ Because the criteria in the Standards effectively constitute a proxy for quality of life, they directly contravene OCR's Bulletin and federal civil rights laws.

Long term prognosis, especially for persons with disabilities, can lead to erroneous, inconsistent, and subjective decision-making in violation of federal antidiscrimination laws. People with disabilities and older adults can outlive the prognoses doctors ascribe to them, often by decades.

Instead of the discriminatory process in the Standards, triage decisions should be governed by individualized assessments of the patient's potential for survivability to discharge if provided for treatment for COVID-19.

F. The Standards fail to require the provision of reasonable accommodations to an individual's disability and reasonable modifications of the triage process.

The Standards do not mention requirements under the ADA and Section 504 to make reasonable accommodations for people with disabilities. Nor do they remind health care facilities of their federal and state anti-discrimination obligations to make reasonable modifications to their policies and practices when necessary to allow persons with disabilities to enjoy the benefits and services they provide. For instance, certain triage criteria, such as limitations on how long

²³ See, Joseph Stramondo, COVID-19 Triage and Disability: What Not to Do, Bioethics.net, March 30, 2020, available at <http://www.bioethics.net/2020/03/covid-19-triage-and-disability-what-not-to-do/>.

²⁴ The prevalence of unconscious bias in the provision of health care generally is well documented. See Cholè FitzGerald & Sania Hurst, Implicit Bias in Healthcare Professionals: A Systemic Review, 18 BMC Med. Ethics (2017) available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5333436/> (meta-analysis of 49 articles on the impact of implicit race and gender bias in the provision of medical care concludes that "healthcare professionals exhibit the same levels of implicit bias as the wider population" and that bias is "likely to influence diagnosis and treatment decisions and levels of care in some circumstances"); see also Clarissa Kripke, Patients with Disabilities: Avoiding Bias When Discussing Goals of Care, 93 Am. Fam. Physician 192 (2017) available at <https://www.aafp.org/afp/2017/0801/p192.html> ("[f]alse assumptions about patients' quality of life can affect prognosis" and even "result in premature withdrawal of life-preserving care.").

²⁵ The Department of Health and Human Services rejected Oregon's plan to ration Medicaid services in the early 1990s that included criteria based upon quality of life and likelihood of treatment returning the patient to an asymptomatic state, concluding that such criteria violate the ADA based on stereotypical assumptions about people with disabilities' quality of life. See Timothy B. Flanagan, ADA Analyses of the Oregon Health Plan, 9 Issues in Law & Medicine 397 (1994) (reprinting federal analyses that Oregon's proposals to ration health care violated the ADA).

patients may stay on a ventilator without demonstrated improvement, may have a disproportionate, negative impact on individuals who are no less likely to recover, but may do so more slowly due to a pre-existing disability.²⁶ Similarly, individuals who are admitted to the hospital with a personal ventilator should not have them reallocated or removed for another individual.

Patients with disabilities may require specific accommodations in communicating their needs and preferences regarding treatment, including access to interpreters and specialized assistive technology. It is critical that all reasonable steps be taken to ensure guardians, family members, and health care agents are afforded an equal opportunity to communicate with the disabled individual, their treating clinicians, and the triage assessment team. If necessary, this communication should be facilitated through specialized interpreters, telephonic or video technology that is effective for, and accessible to, the person and their supporters.

Finally, 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 accommodation should be allowed with proper precautions taken to contain the spread of infection.²⁷

OCR Must Protect All Oklahoma Residents Without Discrimination

In Oklahoma, residents with disabilities, older adults and incarcerated people with co-morbid conditions are experiencing intense fear and anxiety, not only because they are at heightened risk of contracting the COVID-19 virus, but because they expect to be denied lifesaving care in the event health care rationing goes into effect under the attached Standards.

For this reason, ODLIC request that your Office immediately investigate and issue a finding that the Standards unlawfully discriminate against these individuals in violation of federal law. Urgent action is needed given the pace at which the pandemic is spreading and the rising demand on health care resources.

We further request that your Office advise Oklahoma that it must eliminate triage criteria based on life limiting co-morbidities and long-term prognosis, and suggest that it develop revised, mandatory, non-discriminatory Crisis Standards of Care. Those revised Standards must:

- 1) prohibit consideration of disability or age independent of its impact on short term survival from COVID-19;

²⁶ See Kripke, Patients with Disabilities, supra, n. 36, 96 Am. Family Physician at 192 (patient with cognitive limitations and chronic conditions “recovering slowly from an acute, temporary illness” mistakenly referred to hospice due to undue concerns reflecting stereotypical assumptions).

²⁷ See, e.g., COVID-19 visitor policy of Rush University Medical Center, Illinois, available at <https://www.rush.edu/patients-visitors/covid-19-resources/rush-coronavirus-covid-19-patient-and-visitor-updates>.

- 2) prohibit any implementation of the Standards that would result in discriminatory treatment or impact on populations protected by Title VI of the Civil Rights Act of 1964, the Age Discrimination Act of 1975, the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Patient Protection and Affordable Care Act (ACA);
- 3) include an explicit assurance that all individuals are qualified for, and eligible to receive, lifesaving care, regardless of diagnosis, functional impairment or activities of daily living needs;
- 4) ensure that all triage decisions must result from individualized assessments based on objective medical evidence;
- 5) eliminate “life-limiting co-morbidities” or “long term prognosis” as factors in triage scoring protocols;
- 6) eliminate life-cycle and instrumental value/reciprocity principles as a “tie-breaker,” when individuals otherwise have similar priority scores; and
- 7) require that the Standards include reasonable accommodations/modifications of the triage protocol for people with disabilities.

Thank you for your attention. We look forward to your response.

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