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Civil rights leaders call for federal intervention in Oregon's discriminatory health care rationing plan

Oregon plan harms people of color, people with disabilities, older adults

Portland, Oregon—Disability Rights Oregon led a letter from 21 state and national organizations and four Oregon residents denouncing the devastating consequences of Oregon's plan to ration health care during the pandemic. The letter to the Office for Civil Rights at the U.S. Department of Health and Human Services (OCR) cites the negative impact this plan will have on people of color, people with disabilities, immigrants and seniors. The letter asked OCR to find that Oregon's Crisis Care Guidance discriminates against people of color, people with disabilities and seniors in violation of federal law.

"We are scared," said Ross Ryan, a Mt. Angel resident with an intellectual disability who joined the civil rights complaint. "No one should have to worry about whether a doctor will listen to you or treat you when you are really sick just because you have a disability."

"Every week, we see more deaths in Oregon and we know people with disabilities, people of color, immigrants and older adults are being hit the hardest," said Jake Cornett, Executive Director of Disability Rights Oregon. "We've demanded state leaders address problems with Oregon's Crisis Care Guidance to safeguard the civil rights of Oregonians, yet we've seen no response. If Oregon's leaders won't step-up to ensure state policies do not discriminate before the next surge of this pandemic emerges, we'll look for leadership elsewhere. Our families cannot afford to wait."

Reports in Oregon show communities of color are disproportionately impacted by COVID-19. For example, while 13.3 percent of Oregonians are Hispanic, they constitute 29.1 percent of all COVID-19 deaths according to Oregon's May 5 weekly COVID-19 report. The State has failed to report this data for people with disabilities.

"Though Oregon was the first state admitted to the Union with exclusion laws written into its state constitution, and its legacy of racism, xenophobia and disparate treatment of immigrants and minorities is well documented, non-discriminatory access to life saving medical care for Oregon residents must clearly be an unalienable right," said Marcus C. Mundy, Executive Director of the Coalition of Communities of Color. "COVID-19 provides another opportunity for America, and Oregonians, to demonstrate that even in crisis, perhaps especially in crisis, we adhere to our core principles that all life is valuable, and all in America must be treated fairly and equally."

Civil Rights Leaders Demand Changes

The civil rights leaders seek changes to Oregon's Crisis Care Guidance that include the following protections for people with disabilities, people of color and older adults:

- No categorical exclusions. No person will be disqualified from receiving critical care solely on the basis of their disability, race, age, or other protected class.
- A prohibition on coercive Do Not Resuscitate or Do Not Intubate medical orders.
- No reference to specific disabilities as a basis to reduce the likelihood that those individuals would receive critical care.
- No consideration of life expectancy or the availability of resources in the longer term as a basis to deny critical care treatment.
- No one be denied care based on stereotypes, assessments of quality of life or judgments about a person's "worth" based on the presence or absence of disabilities or other factors.
- All rationing decisions must be based on individualized patient assessments by clinicians using the best available objective medical evidence. This means that rationing decisions cannot be based on discriminatory assumptions about a person's disability, medical conditions, race, or age.
- Making modifications to the assessment tools used under the Guidance if a person cannot be accurately and fairly assessed due to a disability.
- Making modifications for people whose disabilities might require a longer period of treatment—for example, on a ventilator—in order to ensure an equal opportunity to benefit from the treatment.

Read the full text of the letter here.

Organizations and Individuals Joining the Civil Rights Complaint

Joining Disability Rights Oregon in this complaint were 14 civil rights and advocacy organization in Oregon representing the interests of people with disabilities, older adults, immigrants and people of color; four Oregon residents who fear discrimination; six national advocacy organizations and the former Principal Deputy Assistant Attorney General in the U.S. Department of Justice Civil Rights Division.

- Oregon Organizations: Disability Rights Oregon; The Arc of Oregon; ACLU of Oregon; Coalition of Communities of Color; Independent Living Resources; Latino Network; Native American Youth and Family Center; Oregon Consumer League; Oregon Council on Developmental Disabilities; Oregon Self Advocacy Coalition; Oregon State Council for Retired Citizens; United Seniors of Oregon, Unite Oregon and Urban League of Portland.
- Oregon Residents who Fear Discrimination: Ryan Ross of Mt. Angel is a person with an intellectual disability; Timothy Roessel of St. John is a person with multiple disabilities who survived COVID-19; Annadiana Johnson of Forest Grove is an older adult with underlying health conditions living in a retirement community and Nicole Charpentier of Portland is a person with cerebral palsy.
- National Organizations: The Arc of the United States; Autistic Self Advocacy Network; Bazelon Center for Mental Health Law; Center for Public Representation; Disability Rights Education & Defense Fund; Justice In Aging and Sam Bagenstos, former Principal Deputy Assistant Attorney General in the U.S. Department of Justice Civil Rights Division.

About Disability Rights Oregon

Disability Rights Oregon upholds the civil rights of people with disabilities to live, work, and engage in the community. The nonprofit works to transform systems, policies, and practices to give more people the opportunity to reach their full potential. For more than 40 years, the organization has served as Oregon's Protection & Advocacy system.

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DRO | Disability Rights Oregon

May 8, 2020

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

Re: Complaint Regarding Oregon's Crisis Care Guidance

Dear Mr. Severino:

We write to ensure non-discriminatory access to life-saving medical care for Oregon residents from all backgrounds, including people with psychiatric, developmental, intellectual and physical disabilities, individuals from communities of color, older adults, immigrants, and prisoners with co-morbid medical conditions who contract COVID-19. We were heartened to see both HHS' March 28th Bulletin and April 16th resolution to a complaint filed in Pennsylvania in which OCR stated: "We must ensure that triage policies are free from discrimination both in their creation and their application, and we will remain vigilant in achieving that goal."

We are filing this Complaint challenging Oregon's 2018 Crisis Standard Guidance ("Guidance") and specifically Appendix E, Oregon Model for Triage and Allocation of Critical Care Resources in a Health Care Crisis.[1] This Guidance may jeopardize the lives of people with disabilities, older adults, individuals from communities of color, prisoners, and others with co-morbid conditions in violation of Title II of the Americans with Disabilities Act (ADA), Title II and Title VI of the Civil Rights Act, 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.

As described below, the Guidance lacks any statement about non-discrimination, lacks any commitment not to exclude people based upon disability or age, lacks any mention of reasonable accommodations for persons with disabilities, and explicitly includes allocation criteria that consider resource utilization, co-morbid conditions, and long-term prognosis which effectively deprioritize individuals with disabilities, older adults, and individuals from communities of color.

Although the situation in Oregon changes daily, arguably the State may be past its initial anticipated peak in COVID-19 transmission. However, the current Guidance must be significantly revised before the next surge in this pandemic emerges in Oregon. At that point the demand for care may exceed capacity, prompting life-or-death decisions regarding

[1] Oregon's Guidance can be found at https://www.theoma.org/CrisisCare

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Disability Rights Oregon is the Protection and Advocacy System for Oregon

the allocation of scarce medical resources. We understand that public officials and health care institutions must make difficult choices about how to allocate care, but it is critical that OCR take immediate steps to ensure that life-saving care is not illegally withheld from people with disabilities, people of color, older adults, and others with co-morbid conditions in Oregon, due to discriminatory triage criteria endorsed by the state.

As the COVID-19 pandemic progresses, it amplifies profound, preexisting inequalities in our society and health care system. Many Native American people, African-American people, Hispanic people, people from other communities of color, people with disabilities, immigrants, institutionalized persons, and working class Americans already experience negative health outcomes at higher rates when compared to their white, non-immigrant, or affluent peers. Early indicators show the effect of COVID-19 is following a similar trajectory. People of color and immigrants are frequently employed in essential positions and are working in contact with the public during the Governor's stay at home order. We have long known that women of color make up the largest group of personal care aides, home health aides, and nursing assistants who provide direct care to older adults and people with disabilities. These essential workers are at elevated risk of exposure to COVID-19 due to their close contact with patients. People of color, people with disabilities, older adults, and immigrants are also disproportionately unhoused, underhoused, or living in communal settings where they do not have adequate space to socially distance themselves from others who may be sick.

At the same time, these same communities have long received inadequate medical care, been exposed to numerous environmental hazards, and been denied adequate medical insurance. This has led to worse health outcomes and shortened life expectancy for people of color, people with disabilities, and immigrants compared to others in the United States. As a result of systemic unequal treatment, these communities disproportionately have diagnoses of diabetes, respiratory disease, heart disease, liver disease, neurologic conditions, and high blood pressure. These same conditions predispose these communities to endure the worst outcomes after COVID-19 infection. Oregon's Guidance would deny lifesaving care to people with these conditions, which are known to disproportionately affect people of color, older adults, and people with disabilities.

Considering that members of these communities are already more likely to be exposed to COVID-19 and more likely to need intensive care once they are infected, it would be an even greater injustice to deny them the care they need once they are infected, relying on resource allocation criteria that reflect existing discrimination, such a pre-existing conditions, long-term prognosis, and resource utilization. Oregon's Guidance cannot, on its own, redress centuries of inequality, but it should not reinstitute that discrimination in deciding who should receive lifesaving care. 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, long-term prognosis, and age, must be eliminated from the Guidance in order to comply with federal law.

I. Complainants

The Arc of Oregon's mission is to provide advocacy, support, and services to children and adults with intellectual and developmental disabilities across the state. The Arc of Oregon in Multnomah, Clackamas, and Washington Counties shares the mission of the statewide organization and has been operating in the Portland area for 67 years. It has a hard-earned reputation of offering advocacy and inclusive programs for people with intellectual and developmental disabilities. It seeks to bring the voices of people experiencing intellectual and developmental disabilities to the forefront, and to promote their inclusion as a guiding principle in our programming.

ACLU of Oregon is a nonpartisan organization dedicated to the defending and advancing civil liberties and civil rights. The ACLU believes that the freedoms of press, speech, assembly, and religion, and the rights to due process, equal protection and privacy, are fundamental to a free people. The ACLU advances and defends civil liberties and civil rights through activities that include litigation, education, and lobbying.

The Coalition of Communities of Color is an alliance of culturally-specific community based organizations in Oregon with representation from the following communities of color: African, African American, Asian, Latino, Middle Eastern and North African, Native American, Pacific Islander, and Slavic. The Coalition supports a collective racial justice effort to improve outcomes for communities of color through policy analysis and advocacy, environmental justice, culturally-appropriate data and research, and leadership development in communities of color.

Disability Rights Oregon's (DRO) mission is to promote and defend the rights of individuals with disabilities. DRO envisions a society in which persons with disabilities have equality of opportunity, full participation and the ability to exercise meaningful choice. Since 1977 Disability Rights Oregon has been the Protection and Advocacy System for the State of Oregon.

Independent Living Resources is a non-profit organization dedicated to helping people with all disabilities. Independent Living Resources was founded in 1957 and works to promote the philosophy of Independent Living by creating opportunities, encouraging choices, advancing equal access, and furthering the level of independence for all people with disabilities.

Latino Network was founded in 1996 by community leaders who grew concerned about the lack of adequate resources to meet the needs of the growing Latino community. Since then, the Latino Network has evolved to become an organization that encompasses transformational programs aimed at educating and empowering Latinos in Multnomah County, Oregon.

Native American Youth and Family Center is a family of numerous tribes and voices who are rooted in sustaining tradition and building cultural wealth. It provides culturally-specific programs and services that guide our people in the direction of personal success and balance through cultural empowerment. Its continuum of lifetime services creates a wraparound, holistic healthy environment that is Youth Centered, Family Driven, and Elder Guided to enhance the diverse strengths of Native youth and families in partnership with the community through cultural identity and education.

Oregon Consumer League has worked for 50 years to protect Oregonians' rights through education, policy development and advocacy. A critical part of that work is to promote sound policy and governmental regulation in the interest of consumers and to help ensure effective enforcement.

Oregon Council on Developmental Disabilities works to create social and policy change in Oregon so that people with developmental disabilities, their families and communities may live, work, play, and learn together. Council Members are appointed by the Governor of Oregon. The Council includes self-advocates, family members of people with developmental disabilities, representatives of advocacy organizations, community organizations that provide services and supports to people with developmental disabilities, and representatives of state agencies that receive federal funding on behalf of people with developmental disabilities.

Oregon Self Advocacy Coalition (OSAC) is an organization fighting for the rights of people with intellectual and developmental disabilities. Operated by people with disabilities, OSAC organizes and advocates for full inclusion in society. It works to reverse the assumption that people with disabilities deserve only limited roles in society. OSAC represents self-advocates in Oregon.

Oregon State Council for Retired Citizens (OSCRC) is a non-profit, non-partisan organization dedicated to advocating for a good quality of life for seniors and people with disabilities. The Council was founded in 1969 to represent the interests or Oregon's seniors. The Council is a state affiliate of the National Council on Aging.

United Seniors of Oregon is a non-profit, non-partisan organization dedicated to advocating for a good quality of life for seniors and people with disabilities. United Seniors was founded in 1979 to advocate for better policies for seniors in Oregon. United Seniors is a state affiliate of the National Council on Aging.

Unite Oregon is led by over 13,000 people of color, immigrants and refugees, rural communities, and people experiencing poverty working across Oregon to build a unified intercultural movement for justice.

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

Ross Ryan is 51-years-old and lives in Mt. Angel, Oregon. He identifies as having an intellectual disability and is an active advocate. He is a member of OSAC as well as a member of the executive committee of Oregon's Developmental Disability Coalition. He has spent his life advocating for the equal rights of people with disabilities and full inclusion in society. Ross lives independently and is interested in meteorology, puzzles, camping, and needle point. He is worried that people with disabilities will not get public safety information regarding COVID-19 in an accessible way. This would result in people like him not knowing how to get to the hospital or how to talk to their doctors once they get there.

Timothy Roessel is 55-years-old and lives in St. John, Oregon. Timothy has multiple disabilities, including lungs damaged in a scuba accident when he was young. In March 2020, he was presumed positive for COVID-19. He had a high fever, cough, and a tightness of chest making it difficult to breathe. "It was like having a bucket on my chest that someone was slowly filling with sand." However, he was denied a COVID-19 test and related treatment due to rationing guidelines that did not make him a high priority despite his physical disabilities. He survived the ordeal but is concerned that his remaining lung functioning has been permanently reduced. He also worries about others like him that will be denied care due to assumptions or stereotypes about their disabilities and quality of life.

Annadiana Johnson is a 67-years-old woman who lives in a retirement community and uses a scooter or walker to ambulate. She has fibromyalgia, heart disease, chronic obstructive pulmonary disease, osteoporosis, and severe dietary restrictions. She does not have a car and uses mass transit to get to her doctor and out into her community. During this pandemic, she has not consistently had access to personal protective equipment that she needs to go out safely. She is also very worried about having safe, equal access to medical care because of her disabilities. For example, if she does get sick, she may not have safe access to a test. Even if she finds a safe way to get a test or get to the hospital for care, based on the current guidance, she does not know if the hospital would even consider her for treatment given her multiple disabilities or accommodate her based on those same disabilities. She is worried about the lack of accommodations for her physical and other disabilities. She is locked at home and is afraid.

Nicole Charpentier is a 39-years-old woman who uses a wheelchair. She identifies as having cerebral palsy and asthma. In March 2020, she was feeling very sick and having a hard time breathing. Her doctor recommended that she go to the hospital because she was experiencing COVID-19 symptoms. When she got to the hospital with her personal care worker, the physician argued with her regarding her disabilities and whether she should get any accommodations or access to needed medical services. This same physician also recommended that her personal care worker maintain a six-foot distance regardless of her care needs. She is worried that if she ever needs medical care again, she will have to fight for care and her rights to accommodation and to be free from discrimination.

This Complaint follows similar actions filed with the OCR against state crisis Guidance in Washington, Alabama, Tennessee, Massachusetts, Utah, Kansas, New York and Pennsylvania, and incorporates by reference the legal arguments set forth in the Washington complaint.[2]

II. Oregon Crisis Guidance of Care

A. Background

Disability Rights Oregon (DRO) first reached out to the Governor's office on April 1, 2020, notifying the Governor and her staff that DRO is "already receiving reports of people with intellectual disabilities with COVID being told by physicians that they should agree to Do Not Resuscitate orders." *See* previous OCR Complaint Ref. # 22090147. On April 10, 2020, DRO also discussed the Guidance with the Governor's staff. While the Guidance clearly states that "clinician-perceived quality of life" should not be a basis for care decisions; elsewhere, the Guidance permits the use of disability indicators that are inconsistent with federal and state law. DRO asked the Governor repeatedly to modify the Guidance to be consistent with HHS guidance and well-established legal protections against discrimination. Given that health care discrimination has already occurred in Oregon, DRO asked the Governor for clear, concise crisis care information be issued to health systems stating that disability discrimination will not be tolerated. DRO has not received a response addressing each of these urgent requests nor any modified version of the Guidance.

B. The Oregon Guidance

There are several glaring omissions from the Guidance that must be rectified including prohibiting discrimination and eliminating opportunities for discrimination including the Guidance's use categorical exclusions, reliance on a resource allocation, and comorbidity limitations that exclusively look at long-term prognosis. There is also a complete lack of reference to the well-established right to reasonable accommodation.

1. Prohibit discrimination against all protected classes.

The Guidance makes no mention of avoiding discrimination, healthcare inequities, conscious and unconscious bias, and the inherent challenges of predicting outcomes of all protected classes. While the Guidance does acknowledge that several factors are not relevant, see page 7 of the Guidance's "Ethical Framework for Health Care in Times of Crisis," it fails to mention many other factors that should be explicitly prohibited in decision-making, including disability or pre-existing conditions.

The Guidance should be modified to conform to OCR's Bulletin which has directed state officials and hospitals "to ensure that entities covered by civil rights authorities keep in mind

[2] These OCR complaints are available at https://www.centerforpublicrep.org/covid-19-medical-rationing/

their obligations under laws and regulations that prohibit discrimination on the basis of race, color, national origin, disability, age, sex."

The "Ventilator Allocation Guidelines" from the New York State Task Force on Life and the Law is a useful model in that it addresses the discriminatory pitfalls of an allocation system and related "quality of life" determinations:

> "Quality of life judgments must not serve as a substitute for ethically sound principles that are available for public scrutiny. The Guidelines must reflect our common duty to protect the rights of the disabled, even while potentially encompassing them in an allocation system."

To correct the existing omission in Oregon Guidance's "Ethical Framework" and prevent decisions based upon potentially discriminatory "quality of life" factors, the following language should be included at the beginning of the Guidance:

Importantly, to protect against discrimination, the triage team protocol would NOT be based on morally or scientifically irrelevant considerations such as socio-economic status, race/ethnicity, gender identity, sexual orientation, national origin, immigration status, faith orientation, parental status, ability to pay, insurance coverage, or disability, nor based solely on age; instead, the best available medical information will be used to assess the potential to benefit from scarce resources in terms of likelihood of survival.

2. Eliminate categorical exclusions to avoid discrimination.

The Guidance includes categorical exclusions on the basis of diagnosis or functional impairment that would deny individuals access to any critical care treatment. For example, Appendix E describes several overly broad exclusionary categories that do not qualify for any life-saving treatment, such as "liver disease, neurologic disease, and heart failure." *See* Appendix E-2. The categories plainly discriminate against persons with specific conditions, without regard to individual evaluations, objective medical criteria, or individually-specific survival determinations. These discriminatory categorical exclusions should be removed. These categorical exclusions may have also served as a discriminatory basis for a hospital to preemptively seek DNR's for clients with developmental disabilities. *See* DRO's first OCR complaint (see Ref. # 22090147). The Guidance should expressly prohibit preemptory do-not-resuscitate or do-not-intubate orders. DNIs and DNRs are extraordinary medical decisions and should only be entered into after getting full and robust informed consent, in a language appropriate to the individual's need and after the opportunity to consult with loved ones.

3. Eliminate reliance on resource utilization to avoid discrimination.

The Guidance directs that, in the absence of a medical condition which satisfies the exclusionary criteria, critical care allocation decisions should be based upon four "additional

criteria". *See* Appendix E-4. While the first two criteria (likelihood of death and likelihood of survival and recovery from the current illness) are appropriate, the third criteria is problematic because it limits life-saving treatment to resource utilization. Not surprisingly, persons with disabilities and those who have experienced longstanding health inequities based upon race or age are far more likely to need more treatment resources – in the short or long-term – to recover from the presenting illness. As a result, treatment decisions that deny life-saving care to those who require more health care resources to recover, but have the same probability of recovering with such resources as other patients, are inherently discriminatory, and severely prejudice persons with disabilities, older adults, and individuals from communities of color.

4. Eliminate reliance on co-morbid conditions and projections of long-term prognosis in order to ensure life-saving treatment decisions are only based on clinical decisions concerning short-term survivability.

The fourth criteria for scare resource allocation – co-morbid conditions and long-term prognosis – is even more problematic and should be eliminated. This criterion demonstrably discriminates against persons with disabilities, older adults, and individuals from communities of color who present with pre-existing conditions. This decision factor reflects specific disabilities or conditions that are not tied to the core variable – short-term survivability. This factor places individuals with chronic illnesses and disabilities that shorten long-term lifespan at a disadvantage for accessing treatment. Moreover, there is no limitation whatsoever on the concept of long-term. Health care decisions that are based upon unlimited long-term prognosis fail to account for the significant uncertainty surrounding long-term survival probabilities. Many clinicians lack expertise necessary to accurately predict long-term prognosis for people with complex care needs, disability, and chronic conditions. Use of long-term survival alone is likely to have discriminatory results.

5. Include the Right to Receive Reasonable Accommodations

The Guidance makes no mention of reasonable accommodations in the Modified Sequential Organ Failure Assessment (MSOFA) necessary to ensure equal treatment of individuals with disabilities or pre-existing organ conditions. Accommodations should be made: (1) in calculating the MSOFA score, in order to adjust for and accommodate pre-existing disabilities; (2) in communicating with persons with disabilities, in order to ensure accurate information is obtained and conveyed; and (3) in allowing support persons to assist or accompany persons with disabilities. For example, the MSOFA may disadvantage specific disability categories, such as chronic ventilator users, that start at a higher SOFA score as their "baseline" condition. The Oregon Guidance must include provisions for ensuring people with underlying conditions not related to COVID are not penalized in the rating system during an acute care episode.

The Guidance is also silent regarding whether a covered entity can permit allocation or re-allocation on the basis of duration of need. Duration of need for ventilators, oxygen, and other resources is often greater for people with underlying but treatable medical conditions. Treatment allocation decisions may not be made based on the perception that a person's disability may require the use of greater treatment resources. In the context of re-allocation decisions, reasonable modifications must be made where needed by a person with a disability to have equal opportunity to benefit from the treatment.

III. Oregon Guidance Violates Federal Law

A. Legal Authority

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 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.[3]

Section 504 of the Rehabilitation Act similarly bans disability discrimination by recipients of federal financial assistance, including Oregon 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

[3] *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.

to avoid discrimination. 45 C.F.R. § 92.205. Section 1557 also forbids discrimination on the basis of race, color or national origin in the delivery of health care through its incorporation of Title VI of the Civil Rights Act of 1964, 42 U.S.C. §2000d, *et seq.* Title VI of the Civil Rights Act prohibits discrimination based on race, color, or national origin in all federally-funded programs. Title II of the Civil Rights Act, 42 U.S.C. §2000a, *et seq.*, prohibits denial of the services of a place of public accommodation on the basis of race, religion, color, or national origin. All hospitals in Oregon are places of public accommodation and receive substantial Medicaid, Medicare, or other federal funding. 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. Assessments of long-term prognosis based on "significant life limiting co-morbidities" are prone to discriminatory assumptions, unconscious bias, and clinical error.

The Guidance provides no objective, reliable, or consistent means of informing decisions on long-term prognosis. It establishes no limit at all on the concept of long-term, meaning that a prognosis of deterioration or death years or even decades from now is a permissible factor in allocating critical care resources. While predictions of future health deterioration, sickness, or death are inherently speculative, projections of the course of illness over an unlimited and undefined period of time are plainly unreliable and potentially discriminatory, likely to reflect unconscious bias, and unsupported by clinical research.

Additionally, populations whose health and longevity are already negatively impacted by inequities in access to care (such as people with psychiatric disabilities; individuals from communities of color; LGBTQ individuals, incarcerated people, and especially older adults) will be doubly harmed by these criteria, undermining the Guidance's stated goals of equity, transparency and fairness in the rationing process.[4]

The Guidance utilizes criteria, including virtually any medical condition that could impact "a patient's long-term prognosis," *see* Appendix E, E-4, will lead to discriminatory assumptions or reflect unconscious bias in the provision of lifesaving care.[5] Further, the Guidance fails to

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[4] *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/.

[5] The prevalence of unconscious bias in the provision of health care generally is well documented. *See* Cholë 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

include safeguards against such influences in the decision-making process. As a result, the criteria in the Guidance may constitute a proxy for quality of life, and, therefore, contravene OCR's Bulletin and federal civil rights laws.

As Complainant Charpentier's experience in March 2020 demonstrates, questions of diagnosis and related long-term prognosis for persons with disabilities can lead to erroneous, inconsistent, and subjective decision-making in violation of federal anti-discrimination 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 Guidance, triage decisions should be governed solely by individualized assessments of the patient's potential for survivability to discharge if provided for treatment for COVID-19.

C. *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, age, and race.*

No patient should be disqualified from life-saving treatment solely because of underlying co-morbid conditions. Oregon's reliance on these criteria dramatically increases the likelihood that individuals with disabilities, older adults, and individuals from communities of color will be denied life-saving care based on discriminatory assumptions about their quality of life or structural inequities that may impact overall life expectancy. The Guidance factor co-morbidities into the triage process in two distinct ways: 1) in calculating the individualized MSOFA scores; and 2) by establishing additional criteria to deny critical care resources for undefined "medical conditions [that impact] long term prognosis."

It is highly likely that individuals with disabilities will be perceived as having co-morbidities that impact long term prognosis, based on discriminatory assumptions about their conditions, or misperceptions about the value and utility of their lives.[6] 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

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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.").

[6] *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.

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."[7]

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, older adults, and persons of color are more than likely to be placed in exclusionary categories or found to have disqualifying criteria under the Oregon's Guidance, because they have conditions that fit within those categories and satisfy those criteria. 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 long 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 or older adults 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."[8]

D. 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 and people of color, will be denied lifesaving care. The Guidance reinforces current and historical inequities in access to health care, and risk importing quality of life criteria or unconscious bias into the triage process. 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.

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[7] *See*, n. 6, *supra.*

[8] 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.

People with disabilities and persons of color have long experienced discrimination in their access to medical and preventative health care.[9] 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.[10]

Likewise, communities of color have also experienced discrimination and marginalization in the delivery of health care, issues which continue in various forms today.[11] People of color are more likely to experience co-morbid medical conditions like asthma, diabetes, hypertension, and heart conditions,[12] as a result of structural racism, environmental factors, occupational safety and health and lack of access to health care.[13] These health conditions can directly or indirectly factor into the SOFA scoring system, and result in de-prioritization for intensive care under the Guidance.

Data reported from states around the country illustrate the disproportionate impact of COVID-19 on communities of color.[14] In Oregon, state-wide data suggests a similar disparity:

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[9] *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.

[10] 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

[11] For instance, African American women are three to four times more likely to die during or after child birth than are white women. Amy Roeder, America is Failing its Black Mothers, Harvard Public Health Magazine (Winter 2019) available at https://www.hsph.harvard.edu/magazine/magazine_article/america-is-failing-its-black-mothers/.

[12] U.S. Dep't Health & Human Services, Office of Minority Health, Profile Black/African American ("The death rate for African Americans is generally higher than whites for heart diseases, stroke, cancer, asthma, influenza and pneumonia, diabetes, HIV/AIDS, and homicide.") available at https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=61.

[13] Jamila Taylor, Racism, Inequity and Health Care for African Americans, (The Century Foundation 2019) available at https://tcf.org/content/report/racism-inequality-health-care-african-americans/?agreed=1.

[14] *See*, Reis Thebault et al., The Coronavirus is Infecting and Killing Black Americans at an Alarming Rate, Washington Post, April 7, 2020, available at https://www.washingtonpost.com/nation/2020/04/07/coronavirus-is-infecting-killing-black-americans-an-alarmingly-high-rate-post-analysis-shows/?arc404=true; *see also* Yancy, COVID 19 and African Americans, April 15, 2020, available at https://jamanetwork.com/journals/jama/fullarticle/2764789; Artiga et al, Growing Data Underscore that Communities of Color are Being Harder Hit by COVID-19, April 20, 2020 available at https://www.kff.org/coronavirus-policy-watch/growing-data-underscore-communities-color-harder-hit-covid-19/

Oregon COVID-19 Distribution by Race			
Race	Percentage of Population[15]	Percentage tested Positive[16]	Percentage who died[17]
White	86.6	53.1	Not Reported
Black	2.2	2.5	Not Reported
Asian	4.8	3.6	Not Reported
American Indian/Alaska Native	1.8	1.6	Not Reported
Pacific Islander	.5	1.0	Not Reported
Other	Not Reported	25.5	Not Reported
Hispanic	13.3	Not Reported	29.1
Two or more races	3.9	2.1	Not Reported

Incarcerated persons, many of whom have co-morbid conditions, are also at significant risk of contracting COVID-19.[18] 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. These individuals also are at greater risk of requiring hospital level of care and, therefore, finding their access to treatment determined by discriminatory Guidance.[19]

E. The Guidance fails to require the provision of reasonable accommodations to an individual's disability and reasonable modifications of the triage process.

The Guidance does not mention requirements under the ADA and Section 504 to make reasonable accommodations for people with disabilities. Nor does it 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 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.[20] Similarly,

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[15] https://www.census.gov/quickfacts/OR

[16] Published May 5, 2020, https://www.oregon.gov/oha/PH/DISEASESCONDITIONS/DISEASESAZ/Emerging%20Respitory%20Infections/COVID-19-Weekly-Report-2020-05-05-FINAL.pdf

[17] *Id.* Oregon's current data is incomplete regarding the demographics of who has died.

[18] 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/.

[19] *See, e.g.*, https://www.nbcboston.com/news/coronavirus/70-new-deaths-reported-in-mass-as-number-of-coronavirus-cases-tops-25000/2106463/ reporting that nearly half of all deaths in the state - 340, or 44% of the total - came at long-term care facilities and that more than 3,000 residents or health care workers at long-term care facilities have tested positive for COVID-19.

[20] *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).

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.

IV. OCR Must Protect All Oregon Residents Without Discrimination

In Oregon, residents with disabilities, older adults, incarcerated people, and communities of color 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 Guidance.

For this reason, the individual and organizational Complainants request that your Office immediately investigate and issue a finding that the Guidance unlawfully discriminates 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 Oregon 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 Guidance of Care. Those revised Guidance must:

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

2) prohibit any implementation of the Guidance 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, and Section 504 of the Rehabilitation Act of 1973;

3) include an explicit assurance that all individuals are qualified for, and eligible to receive, lifesaving care, regardless of diagnosis, functional impairment, activities of daily living needs, or related resources to meet those needs;

4) ensure that all triage decisions must result from individualized assessments based on objective medical evidence;

5) eliminate undefined "co-morbidities" or "long term prognosis" as factors in triage scoring protocols; and

6) require that the Guidance include reasonable accommodations/modifications of the triage protocol for people with disabilities.

Thank you for your attention. We look forward to your response. You can contact Emily Cooper, Disability Rights Oregon's Legal Director, at ecooper@droregon.org.

Sincerely,

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