



April 14, 2020

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RE: Medical Rationing & Mitigating Harm to People with Disabilities

Dear Ms. Klein and Mr. Buehler:

Thank you for taking time to speak with me and Emily Cooper, Legal Director at Disability Rights Oregon (DRO), on April 10, 2020. I write to both memorialize our communications and request that we use our respective unique authorities to work together, not against, to mitigate the harm that COVID-19 poses to vulnerable Oregonians. The disability community needs the Governor's swift action to make clear that our lives matter. We urgently request that the Governor use her emergency powers to modify the existing crisis care guidance to prohibit discrimination consistent with state and federal laws.

Discriminatory Care Practices Have Already Been Confirmed in Oregon

As you know, I first reached out to the Governor's office on April 1, 2020, when I sent an email notifying you both 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." DRO had already begun a preliminary investigation on March 30th. While the hospital initially denied access to this client, we confirmed that our client was likely coerced by a hospital into signing a DNR and was at imminent risk of harm. On April 2nd, DRO reached out to Oregon Health Authority (OHA) and Office of Developmental Disabilities Services (ODDS) sharing our probable cause of abuse findings in an effort to mitigate the imminent harm to this client and the others in her home (whom likewise received information from the same hospital that they would seek a presumptive DNR without an individualized assessment). OHA notified the Health Facility Licensing & Certification Program (HFLC) office as well.

DRO had two calls with Steve Allen and others from OHA, Lilia Teninty and others from ODDS, and Wendy Edwards from the HFLC on April 2nd and April 3rd. When I asked which state agency has authority to intervene on behalf of this at-risk client, the response from HFLC was a lengthy explanation of the licensing process that required information not within DRO's possession. Based on the information provided during the calls, neither OHA nor HFLC were able to take timely protective action nor provide clear guidance to the hospital about its obligations under state and federal law. We subsequently filed a complaint with HFLC and yesterday received a response stating "[o]ur team and CMS determined there may potentially be Standard-level deficient practices on the part of the hospital in the area of a patient's right to formulate Advance Directives and make DNR/DNI decisions." However, took no action as a result. *See* enclosure. Thankfully, ODDS was extremely helpful during the calls with OHA and HFLC and eventually facilitated direct contact between the client and DRO's attorneys to accommodate the client's communication abilities. We are also continuing to work with ODDS to develop fact sheets for similarly situated clients and their providers facing medical decision making in order to best protect their rights.

Given a discriminatory, unabated hospital practice and continued risk to the disability community served by this hospital, I telephoned Katherine Bartlett and explained I have an urgent life-or-death situation and needed to speak with Ms. Klein as soon as possible. A call was initially scheduled for April 3rd. However, later that day, Ms. Bartlett informed me that the Governor's staff are not permitted to speak with DRO without the General Counsel present. I was informed the soonest Mr. Buehler and Ms. Klein were available is April 6th—three days later. I reiterated this was an urgent matter and that it does not pertain to any litigation between DRO and the State. A call was scheduled on April 6 at 9:00AM. On April 6th, the second scheduled call was canceled. We did not speak until April 10th, long after DRO was successful in getting this discriminatory DNR lifted and the client transferred to a hospital where she received medical care. While I respect the Governor's right to have counsel on the call, it resulted in a delay during an emergency when her office could have used its authority and guidance to protect a vulnerable Oregonian when DRO was afraid we alone could not.

DRO's Federal Authority to Protect and Promote the Rights of Oregonians with Disabilities is Maximized When We Work in Concert

While DRO has considerable federal authority to protect our clients, our efforts are only maximized when we can work in concert with the state and its providers. DRO was designated Oregon's Protection and Advocacy Agency by Governor Straub in 1977. DRO is federally mandated to provide protection and advocacy services to individuals with disabilities in the Oregon pursuant to the Developmental Disabilities Assistance and Bill of Rights ("DD") Act, 42 U.S.C. § 15041, *et seq.*, the Protection and Advocacy for Individuals with Mental Illnesses ("PAIMI") Act, 42 U.S.C. § 10801, *et seq.*, the Protection and Advocacy for Individual Rights ("PAIR") Act, 29 U.S.C. § 794e, and the regulations promulgated thereto, and ORS 192.517. Under these laws, a primary component of DRO's mandate is to conduct a "full

investigation” when DRO receives a report of abuse or neglect or has probable cause to believe that an individual with a disability either has been, or is at risk of being, abused or neglected. *See e.g.* 42 U.S.C. § 15043(a); 42 CFR § 51.2. In order to carry out this mandate, DRO has been granted broad access to individuals with disabilities, as well as to records and reports related to their treatment and care. *Alabama Disabilities Advocacy Program v. Tarwater*, 97 F.3d 492, 497 (11 th Cir. 1996); *Center for Legal Advocacy v. Hammons*, 323 F.3d 1262, 1270 (10th Cir. 2003). This authority is unique as it allows DRO to act quickly, gather relevant information, and take protective action to protect and advocate for our clients.

However, in the present case, our access authority was frustrated both by this problematic hospital as well as DRO’s recognition that we must be reasonable in our access authority to ensure that we don’t inadvertently expose our clients or others to this highly communicable virus. We also recognized that traditional advocacy strategies – including seeking emergency injunctive relief from a court – was likely not the best tool to protect this client’s life or others like her given the limited availability of the courts and the limited time we had to get her the services she needed to survive COVID-19. This is why we reached out to you and several key state officials. We sincerely want to be a partner with you as it will take every resource, strategy, and person to work together to limit the number of Oregonians with disabilities who get sick or die from this horrible virus.

The Governor Has the Authority and Must Modify the Existing Oregon Crisis Care Guidance

While DRO is unique in our authority to access people with disabilities and their records, the Governor is unique in her responsibility and related authority to issue clear, unbiased crisis care guidance or executive orders that protect the public and prohibits discrimination. As you are aware, the ADA,¹ the Rehabilitation Act, and their implementing regulations apply to essentially every healthcare provider in the State that will provide necessary medical care during the COVID-19 pandemic. These Acts prohibit discrimination when providing “an aid, benefit, or service that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or the reach the same level of achievement” as that provided to people without disabilities.² Similarly, “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service program or activity” are also prohibited.³

There are no exceptions in federal law that suspend these requirements and authorize discrimination during a public health emergency.⁴ Indeed, only a few days ago the federal

¹ 42 U.S.C. §§ 12132; 12182(a).

² 28 C.F.R. §35.130(b)(1)(iii) (Title II). *See also* 28 C.F.R. § 36.201(a) (Title III) (prohibiting discrimination “in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place

³ 28 C.F.R. §35.130(b)(8) (Title II). *See also* 28 C.F.R. § 36.301(a) (Title III); 45 C.F.R. §§ 84.4(b)(iii) and 84.52(a)(3) (Sec. 504); 28 C.F.R. § 41.51(b)(3) (Sec. 504).

⁴ United States Department of Justice, *Emergency Management Under Title II of the Americans with Disabilities Act*, at 1 (July 26, 2007) available at <http://www.ada.gov/pcatoolkit/chap7emergencygmt.htm> (“One of the

Office for Civil Rights within the U.S. Department of Health and Human Services (OCR) issued a bulletin with guidance for states that made it clear that the federal laws discussed above remain in effect.⁵ As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.

It is imperative that your office promptly issue guidance to reinforce the OCR bulletin and to make clear that the lives of all Oregonians with disabilities have value and that they shall receive equal consideration when decisions are made about who receives potentially life-saving treatments. On behalf of the Oregon disability community, we also respectfully request that your office consider the following problems and suggested modifications to the existing crisis care guidelines

Lack of Clarity in Existing Crisis Care Guidance Provides for Discriminatory Decision Making

During our April 10th phone call, we also discussed the Oregon Crisis Care Guidance (the "Guidance"). 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. In bold below, you will find DRO's recommendations for modifications to the Guidance.

The Guidance may not include categorical exclusions on the basis of diagnosis or functional impairment. The Guidance appears to make a distinction between non-life-threatening disability and life-threatening disability (p. G-4). The Guidance also states "access to critical care would be limited for those with medical conditions associated with low likelihood of long-term survival [...] non-life-threatening disability and 'social worth' are NOT exclusion criteria." Notably, **"life-threatening disability" should be defined to limit broad interpretations based on biased "quality of life" considerations.** This lack of distinction is

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."); see also Wendy F. Hensel & Leslie E. Wolf, *Playing God: The Legalities of Plans Denying Scarce Resources to People with Disabilities in Public Health Emergencies*, 63 Fla. L. Rev. 719, 737-30 (May 2011) cited by Disability Rights Education & Defense Fund, *Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing on the Basis of Disability*, (March 25, 2020).

⁵ HHS Office for Civil Rights in Action, *Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)* (March 28, 2020). On March 31, 2020, the OCR updated its bulletin, leaving in the quoted language above, but adding explicit language regarding healthcare providers' obligation to provide effective communication to individuals who are deaf, hard of hearing, blind, low vision, or have speech disabilities and to address the needs of individuals with disabilities in emergency planning.

ripe for bias and discrimination in allocation of finite resources. This distinction may have also served as the basis for the hospital, referenced above, to preemptively seek DNR's for clients with developmental disabilities.

The Guidance may not include implicit or explicit quality of life assessments as an allocation criterion. In your letter to DRO dated April 7, 2020, you reference the following language in the Guidance: "[I]n a public health crisis, decisions about who should receive critical care and other medical services should be based on clinical experience using objective clinical information, just as they are in noncrisis situations. Care decisions should not be based on non-clinical factors such as race, ethnicity, clinician perceived quality of life, profession, social position, or ability to pay." While this is promising language, there is no reference to "disability" as a prohibited, non-clinical factor. **"Disability" should be included in this list of prohibited non-clinical factors.**

The Guidance may not include long-term survival beyond the acute care episode as an allocation criterion. Oregon's Guidance currently permits the consideration of long-term prognosis "when multiple people have the same potential for benefit." This factor must be removed from consideration. This factor places individuals with chronic illnesses and disabilities that shorten long-term lifespan at a disadvantage for accessing treatment and fails 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.

The Guidance may not permit allocation or re-allocation on the basis of duration of need. Duration of need for ventilators, oxygen, and other resources is often continuing 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.

Similarly, the Guidance may only incorporate short-term survival in an individualized fashion and consistent with available standards. For example, the use of the Sequential Organ Failure Assessment (SOFA) may disadvantage specific disability categories, such as chronic ventilator users, that start at a higher SOFA score as their "baseline" condition. The Oregon Guidance relies heavily on a modified SOFA. It is unclear whether the modified SOFA used by Oregon results in a higher starting SOFA score for chronic ventilator users. **The 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 must make special considerations for chronic ventilators users. **Doctors and**

triage teams must not reallocate ventilators from individuals with disabilities who use ventilators in their daily lives. This remains a significant fear among people with disabilities in Oregon.

As I stated on the call, **I am requesting for the Crisis Care Guidance be immediately revised consistent with these principles. Given that health care discrimination has already occurred in Oregon, we also ask that clear, concise crisis care information be issued to health systems with a statement from the Governor.** This information should make clear disability discrimination will not be tolerated. DRO stands ready to join and support the Governor in this effort.

Visitation Policies Must Provide for Reasonable Modifications to Comply with Federal Law

Finally, while we did not raise this on the phone, OHA recently revised visitation guidance on April 5th. DRO has already received concerns about this guidance from local hospitals who seek to have a visitation policy that is consistent with the ADA. OHA's revised guidance requires hospitals to adopt and enforce policies that limit entry to essential individuals. This guidance includes among essential visitors the following: "Guardians or caregivers of patients with altered mental status or intellectual disabilities if in-person visitation is necessary to: facilitate treatment [or] ensure the safety of the patient or facility staff." However, the guidance then states that screening must "Refuse visitation of any essential individual if a patient is being treated for COVID-19; exceptions may be made on a case-by-case basis for end-of-life care as determined by the medical provider in charge of patient's care."

This guidance lacks any reference to visitors who also provide care regarding activities of daily living that are not otherwise available in hospital settings. For example, many individuals with physical disabilities require the presence of a family member, personal care provider, communicator, or similar disability service provider who is knowledgeable about the management of their care, able to assist them with communicating their needs, or able to provide ongoing personal care assistance. These visitors should be allowed provided that proper precautions can reasonably be taken to contain the spread of infection. It is troubling that OHA issued guidance that will have the effect of denying people with all disabilities—not just those with intellectual disabilities—access to these critical support providers. This is especially true when medical decision-making may become necessary due to COVID19.

For example, in the case we referenced above, the hospital refused entry to support providers who would have not merely helped to "facilitate treatment" but also help with understanding the consequences of signing a DNR. This policy guidance from OHA will only increase the likelihood of this scenario repeating. **We ask that OHA reissue this guidance with disability related exceptions, including in the case of COVID positive individuals.**⁶

⁶ Rush Hospital has a promising visitation policy and disability related exception process available here: www.rush.edu/patients-visitors/covid-19-resources/rush-coronavirus-covid-19-patient-and-visitor-updates

Protecting Oregonians with Disabilities Involves Including Us at the Decision-Making Table

I appreciate you taking the time to discuss these matters last Friday. I do understand that we are in a state of emergency. It is precisely because of this emergency that I seek your support in protecting the rights of people with disabilities who are at disproportionate risk of harm during this crisis.

In the coming days, Oregon healthcare providers may be called upon to make decisions many of us never fathomed they would have to make. Now is the time for your office to lead the way and issue guidance for hospitals and healthcare providers regarding which Oregonians will receive potentially limited resources. If the State fails or delays the issuance of clear, timely guidance that protects the lives of Oregonians with disabilities, there will be no way to undo the lethal outcomes that may result should healthcare rationing begin in Oregon.

These suggested modification to the guidelines will also help alleviate the concerns felt by many Oregonians with disabilities who may delay receiving necessary COVID-19-related care out of fear that healthcare providers will not treat them fairly and with dignity, or out of fear that they may lose access to their own life-sustaining equipment. We urge you to act swiftly and issue the guidance set out above.

If the State convenes a task force to develop rationing guidelines, we would like to be a member of or advise the task force. The task force should include persons with disabilities and other disability groups to ensure that the guidelines are lawful, equitable, and respect the rights and dignity of people with disabilities.

Thank you for your consideration of this urgent request and offer to be your partner as we face the days ahead.

Sincerely,



Jake Cornett
Executive Director
Disability Rights Oregon

Enclosures: DRO Email dated April 1, 2020.
Governor's Office Letter dated April 7, 2020.
Oregon Health Authority Health Care Regulation & Control Improvement
Letter dated April 13, 2020.