



2222 West Braker Lane
Austin, Texas 78758
MAIN OFFICE 512.454.4816
TOLL-FREE 800.315.3876
FAX 512.454.3999

April 6, 2020

Governor Greg Abbott
Office of the Governor
P.O. Box 12428
Austin, Texas 78711

Phil Wilson
Acting Executive Commissioner
Texas Health and Human Services
P.O. Box 13247
Austin, Texas 78711

Dr. John Hellerstedt
Commissioner
Texas Department of State Health Services
P.O. Box 149347
Austin, Texas 78714

Dear Governor Abbott, Executive Commissioner Wilson, and Commissioner Hellerstedt:

On behalf of the undersigned groups, I am writing to urge the State to issue guidance on the rationing of healthcare resources that prohibits discrimination against persons with disabilities. We are deeply concerned that without such state guidance, should healthcare resources become insufficient to meet the need caused by the COVID-19 pandemic, Texas hospitals and healthcare providers will resort to rationing these resources in a manner that discriminates against individuals with disabilities and violates federal non-discrimination laws. Our concern is well founded. State officials in Washington, Alabama, and Tennessee issued guidelines for the rationing of medical services and devices like ventilators that illegally consider intellectual disability and traumatic brain injury diagnoses, for example, as well as the perceived lesser quality of life of individuals with disabilities. Accordingly, these states now find themselves the subject of complaints to the U.S. Department of Health & Human Services, Office for Civil Rights (“OCR”) for violations of the Americans with Disabilities Act (“ADA”) and Section 504 of the Rehabilitation Act.

Before the need for rationing arises in Texas, your offices must issue clear guidance that prohibits the devaluing of the lives of persons with disabilities. 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

¹ 42 U.S.C. §§ 12132; 12182(a).

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 OCR issued a bulletin with guidance for states that made it clear that the federal laws discussed above

remain in effect. As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence.⁵

It is imperative that your offices promptly issue guidance to reinforce the OCR bulletin and to make clear that the lives of all Texans 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 undersigned and Texans with disabilities, we respectfully request that your offices issue the following guidance detailing what Texas health care providers must do to care for the lives of all Texans, consistent with the obligations placed on healthcare providers by the ADA and Section 504:

- Decisions about how treatment should be allocated and who should be prioritized must be based on individualized determinations, using current objective medical evidence, and not based on generalized assumptions about a person’s disability. The mere fact that a person has diabetes, depression, an intellectual disability, or a mobility impairment, for example, cannot be a basis for denying care or making that person a lower priority to receive treatment. Similarly, decisions cannot be based on the determination that an individual will acquire a disability should they survive the virus.
- Treatment allocation and prioritization decisions cannot be based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living.

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 of public accommodation”); 45 C.F.R. §§ 84.4(b)(1)(ii) and 84.52(a)(2) (Sec. 504); 28 C.F.R. § 41.51(b)(1)(ii) (Sec. 504).

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/chap7/emergencymgmt.htm> (“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.”); *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.

Quality of life considerations are neither “objective” nor “neutral,” even when couched in seemingly neutral or objective language, and study after study has conclusively demonstrated that people without disabilities significantly and consistently undervalue the quality of life of people with disabilities.⁶ The use of such criteria to allocate or prioritize receipt of healthcare will inevitably lead to the denial of care based on disability.

- Treatment allocation and prioritization decisions cannot be based on the perception that a person with a disability has a lower prospect of survival. While the possibility of a person’s survival may receive some consideration in allocation decisions, that consideration must be based on the prospect of surviving the condition for which the treatment is designed—in this case, COVID-19—and not other disabilities. The decision to withhold care must be based on a clear indication from the person’s individual circumstances, interpreted according to the best available medical evidence in a manner free from bias, that the person will die in the very short term whether treatment is provided or not.
- Treatment allocation and prioritization decisions cannot be based on the perception that a person’s disability will require the use of greater treatment resources. Reasonable modifications must be made if needed by a person with a disability to have equal opportunity to benefit from the treatment. These may include interpreter services or other modifications or additional services needed due to a disability.
- Treatment allocation and prioritization decisions similarly cannot be based on the likely need for a longer duration of care. People with disabilities may require more health care for a longer time to effectively treat COVID-19 than others without underlying disabilities. Considering the longer duration of treatment disregards the obligation to accommodate people with disabilities as the additional time for a treatment to be effective for a person with a disability is an appropriate accommodation to ensure the person has meaningful access to the service.
- Treatment allocation and prioritization procedures developed by healthcare providers must be made available to the public. Healthcare providers must inform patients of their rights, must inform patients of the basis for denying healthcare resources, and must allow for a review of any decision denying such resources.
- Individuals with disabilities who have durable medical equipment, including but not limited to ventilators, retain their right to possess this personal property and their medical equipment cannot be taken away from them in order to allocate that medical equipment to other individuals.

In the coming days, Texas 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 offices to lead the way and issue guidance for hospitals and healthcare providers regarding which Texans will receive potentially limited resources. If the State fails or delays the issuance of clear, timely guidance that protects the lives of Texans with

⁶ Numerous studies have concluded that “[p]roviders often perceive people with disabilities to have a low quality of life when, in reality, most report a high quality of life and level of happiness, especially when they have access to healthcare services and supports that they need to equally participate in their communities.” 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) citing Mary Crossley, *Ending-Life Decisions: Some Disability Perspectives*, 33 Ga. St. L. Rev. 900, 90-01 (2017); see also 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*, available at <https://ssm.com/abstract=3559926> at 9-10.

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disabilities, there will be no way to undo the lethal outcomes that may result should healthcare rationing begin in Texas. These suggested guidelines will also help alleviate the concerns felt by many Texans 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.

Finally, 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. If you have any questions or would like to discuss this further, you may reach me at 512.454.4816.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary Faithfull". The signature is fluid and cursive, with a long horizontal stroke at the end.

Mary Faithfull, Executive Director, Disability Rights Texas, on behalf of:

ADAPT of Texas
Arc of Texas
Center for Public Policy Priorities
Coalition of Texans with Disabilities
Coastal Bend Center for Independent Living
Pauline A. Filipek, MD
Hogg Foundation for Mental Health
National Association of Social Workers – Texas Chapter
RecoveryPeople
The SAFE Alliance
Texas Appleseed
Texans Care for Children
Texas Council for Developmental Disabilities
Texas Democrats with Disabilities
Texans for Special Education Reform
Texas Housers
Via Hope