

April 29, 2020

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

Via email to sarah.hicks@gov.texas.gov and CCOMRequests@gov.texas.gov

CC:

Phil Wilson, Acting Executive Commissioner
Texas Health and Human Services
P.O. Box 13247
Austin, Texas 78711
Via email to Phil.Wilson@hsc.state.tx.us

Dr. John Hellerstedt, Commissioner
Texas Department of State Health Services
P.O. Box 149347
Austin, Texas 78714
Via email to John.Hellerstedt@hsc.state.tx.us

Dear Governor Abbott:

On behalf of the organizations listed below we write today to urge you to adopt a policy that clearly directs health care providers across the state to refrain from discriminating against people with disabilities and chronic conditions in the provision of treatment during the COVID-19 emergency. In Texas, stakeholders in the health care community have developed mass critical care guidelines to guide hospitals and health care providers during a respiratory pandemic or other public health emergency. As you heard from the Texas Catholic Council of Bishops¹ and Disability Rights Texas², organizations representing people with pre-existing chronic conditions and disabilities are concerned that these guidelines are discriminatory and will prevent or limit life-saving care from the people we represent.

As COVID-19 continues to spread through our communities, we are facing unrepresented times. Unfortunately, our state may reach a point where need outstrips our health care capacity. This is a reality that we must face together. Our response cannot be based on discriminatory and outdated ideas about quality of life or the value of people with disabilities and chronic conditions to society. Federal laws – including the American with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act – broadly protect people against discrimination in receiving care. People living with chronic conditions and disabilities must not be denied treatment or deprioritized for COVID-19 care under the medical triage or crisis standards that have already been developed in Texas by hospital systems, or in any statewide direction that is currently being developed. In addition, training for all healthcare providers and triage teams during this crisis should include non-discrimination training and any guidance that is implemented regarding addressing allocation of scarce resources should begin with a non-discrimination clause to inform the decision-making process that follows.

On March 28, the Office for Civil Rights (OCR) at the US Department of Health and Human Services issued a bulletin regarding Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19).³ In the bulletin, OCR reminded federally-funded health programs and activities that Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act prohibit discrimination on the basis of disability, and that these civil rights laws are still in effect. OCR continues, “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 or age. 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.”

¹ <https://txcatholic.org/statement-on-scarce-healthcare-resources/>

² https://www.disabilityrightstx.org/en/press_release/c19rationingguidance/

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

We are concerned that the existing plans individually developed by stakeholders are discriminatory and will harm the people we represent. For example, the Christus Health Crisis Response Guidelines for Hospital and ICU Triage, North Texas Mass Critical Care Guidelines Document Hospital⁴ and ICU Triage Guidelines for Adults and the Baylor Scott and White Health Mass Critical Care Guidelines for Adults/Pediatrics use the same “Exclusion Criteria for Hospital Admission” and the presence of an underlying disability, chronic health condition or co-morbidity is justification to deny hospital admission. All individuals should be eligible for lifesaving care regardless of a diagnosis of, for example, an “advanced untreatable neuromuscular disease (such as ALS or end-stage MS) requiring assistance with activities of daily living or chronic ventilatory support.” It is worth noting that multiple sclerosis (MS) is not a terminal disease, and in this case, utilizing the term “end-stage MS” is not only inaccurate and inappropriate, it is dangerous. In addition, Christus Health guidelines suggest using age as a basis for excluding an individual from hospital-based care when triaging patients. Baylor Scott and White guidelines for pediatric triage also include the following “underlying conditions” as exclusion criteria: chromosomal abnormalities, metabolic diseases, muscular atrophy, cystic fibrosis with FEV1 < 30% or baseline PaO2 < 55 mm Hg, and progressive neuromuscular disorders “with inability to sit unaided or ambulate when such abilities would be developmentally appropriate based on age.”

Every patient must be treated as an individual, not a diagnosis; healthcare providers must not assume that the presence of a specific diagnosis or disability indicates a poor prognosis for near-term survival or inability to respond to treatment. There must be a thorough, individualized assessment and care should not be denied unless it is clear that the individual will not survive in the immediate-term or the treatment is contraindicated. The fact that an individual requires support, minimal or extensive, in daily living is not relevant to a medical analysis of whether that person can respond to treatment.

In other states, these plans have led to legal action. To date, advocates have filed complaints with OCR in response to plans issued in Washington,⁵ Alabama,⁶ Kansas,⁷ Tennessee,⁸ Pennsylvania,⁹ Utah,¹⁰ New York,¹¹ and Oklahoma.¹² Thirty-two bipartisan members of Congress have also expressed concern.¹³

We urge you to work with our organizations in the state to write a plan that is based on individual assessments of each patient. This plan should be written in accordance with the OCR bulletin and should be made publicly available and widely distributed to stakeholders. Several of our groups have endorsed additional guidance, written by disability rights professionals, on how to implement the bulletin in states.¹⁴ This should also serve as additional assistance toward writing a plan that is equitable, just, and does not discriminate against the people we represent.

We look forward to working with you to develop a plan for our state. Please reach out to Simone Nichols-Segers at 512-340-2707 or simone.nichols-segers@nmss.org with questions and next steps.

Sincerely,

American Diabetes Association
American Lung Association in Texas
Children's Defense Fund - Texas
Cystic Fibrosis Foundation

⁴ https://www.dallas-cms.org/tmimis/dcms/assets/files/communityhealth/MCC/GuidelinesAdult_JAN2014.pdf

⁵ https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf

⁶ https://www.centerforpublicrep.org/wp-content/uploads/2020/03/AL-OCR-Complaint_3.24.20.docx.pdf

⁷ <https://www.centerforpublicrep.org/wp-content/uploads/2020/03/Kansas-OCR-complaint-3.27.20-final.pdf>

⁸ <http://thearc.org/wp-content/uploads/2020/03/2020-03-27-TN-OCR-Complaint-re-Healthcare-Rationing-Guidelines.pdf>

⁹ <https://www.centerforpublicrep.org/wp-content/uploads/2020/04/04.03.2020-DRP-OCR-Complaint-with-Exhibit-A-1.pdf>

¹⁰ <https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Utah-OCR-Rationing-Final-.pdf>

¹¹ <https://www.dropbox.com/s/h3hjktdvz3qxes3/2020.04.07%20-%20Ventilator%20Rationing%20-%20OCR%20Complaint%20FINAL.pdf?dl=0>

¹² <http://okdlc.org/wp-content/uploads/2020/04/4.21-Oklahoma-OCR-Complaint-Final.pdf>

¹³ <https://chrissmith.house.gov/news/documentsingle.aspx?DocumentID=406467>

¹⁴ https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf

Epilepsy Foundation Central & South Texas
Epilepsy Foundation of Texas
Hemophilia Association of New York, Inc.
Methodist Healthcare Ministries of South Texas
National Alliance on Mental Illness (NAMI) Texas
National Association of Social Workers - Texas Chapter
National Multiple Sclerosis Society
National Organization for Rare Disorders
Texas Central Bleeding Disorders