



April 16, 2020

The Honorable Laura Kelly
300 S.W. 10th Ave
Topeka, KS 66612

Dear Governor Kelly:

On behalf of the undersigned organizations we write today to express concern with the "Toolkit for COVID-19" issued by the Kansas Department of Health and Environment, thank you for removing the document, and ask to work with you on future efforts. As organizations representing people with pre-existing chronic conditions and disabilities, we are concerned that the Toolkit is discriminatory and will prevent or limit life-saving care from the people we represent if implemented.

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 Our response cannot be based on discriminatory and outdated ideas about quality of life or the value of people with disabilities and chronic conditions to society.

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).¹ 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."

We are concerned that the COVID-19 Toolkit that had been released will harm the people we represent. The guidelines advise that health care providers exclude from treatment people with "advanced untreatable neuromuscular disease", as well as people with "advanced and irreversible immunocompromise" and some people with metastatic cancer. The people listed here are not categorically less likely to benefit from COVID-19 treatment. Instead, this determination has been made

¹ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

on broad categories of diagnosis, not individual assessment. We appreciate that you have withdrawn the plan from your website in recognition that the plan should be revised.

As you know, these plans, including the COVID-19 Toolkit, have led to legal action.² To date, advocates have also filed complaints with OCR in response to plans issued in Washington,³ Alabama,⁴ Tennessee,⁵ and Pennsylvania.⁶ Thirty-two bipartisan members of Congress have also expressed concern.⁷

We urge you to work with our organizations and with disability rights 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. Several of our groups have endorsed additional guidance, written by disability rights professionals, on how to implement the bulletin in states.⁸ 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 Sara Prem (Sara.Prem@lung.org) if you have any questions.

Sincerely,

American Kidney Fund
American Lung Association in Kansas
Crohn's & Colitis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation of Missouri and Kansas
Hemophilia Federation of America
National Hemophilia Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
Susan G. Komen

² https://www.centerforpublicrep.org/wp-content/uploads/2020/03/AL-OCR-Complaint_3.24.20.docx.pdf

³ https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf

⁴ https://www.centerforpublicrep.org/wp-content/uploads/2020/03/AL-OCR-Complaint_3.24.20.docx.pdf

⁵ <http://thearc.org/wp-content/uploads/2020/03/2020-03-27-TN-OCR-Complaint-re-Healthcare-Rationing-Guidelines.pdf>

⁶ <https://www.centerforpublicrep.org/wp-content/uploads/2020/04/04.03.2020-DRP-OCR-Complaint-with-Exhibit-A-1.pdf>

⁷ <https://chrissmith.house.gov/news/documentsingle.aspx?DocumentID=406467>

⁸ https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf