



Protecting and Promoting the Rights of Kentuckians with Disabilities

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April 7, 2020

Andy Beshear
Governor
700 Capitol Ave
Suite 100
Frankfort, Kentucky 40601

RE: Equal access to healthcare for COVID-19 positive Kentuckians with disabilities

Dear Governor Beshear:

Kentucky Protection and Advocacy (P&A) is an independent state agency that protects and promotes the rights of individuals with disabilities throughout the Commonwealth. We and the undersigned associations, interested groups, and individuals with disabilities and their family members are concerned that Kentuckians with disabilities will not have equal access to health care during this medical crisis created by the COVID-19 pandemic.

While we are heartened to see the curve in Kentucky is flattening due to your leadership, we urge you to take action to ensure equal access to medical care for all of Kentucky's citizens, especially if our hospitals are forced to ration treatment and equipment.

As COVID-19 is a novel coronavirus that attacks the lungs, the need for ventilators and Intensive Care Unit (ICU) beds is paramount, but many models predict that at some point the demand for each will exceed Kentucky's supply. We share your hope that the mitigation efforts taken so far will flatten the curve such that our existing resources will be sufficient to handle demand when the peak arrives. However, as news reports tell us, there remain individuals who are ignoring those mitigation measures and Kentucky citizens—including those with disabilities—continue to contract COVID-19. While we hope there will not be discrimination against the disabled, history shows that it will nevertheless likely occur.

Many states have policies that address the allocation of resources, like ventilators, in the event of a natural disaster or pandemic. Ideally, those policies set neutral decision-making rules based on the individual medical condition of the patient. Unfortunately, some states—including Alabama and Tennessee—have adopted policies that discriminate against individuals with disabilities. Alabama's policy, for example, provides that individuals with severe or profound intellectual disabilities are "unlikely candidates for ventilator support." This policy is discriminatory because it is not supported by medical data and requires physicians make decisions based on generalizations and

P&A is a federally mandated program that receives funding from the U.S. Department of Health and Human Services, the U.S. Department of Education and the Social Security Administration.

stereotypes (even if unconsciously) rather than the individual medical condition of the patient.

Kentucky does not provide any guidance for physicians and the healthcare professionals who will be making treatment decisions in light of limited or exhausted resources. The State Emergency Operations Plan does not provide such guidance. Neither does the Kentucky Pandemic Influenza Protocol nor the recently created Crisis Standards of Care: Guidance for the Ethical Allocation of Scarce Resources during a Community-Wide Public Health Emergency, which specifically states that it does not apply to the COVID-19 pandemic. The Cabinet for Health and Family Services responded it “is not in possession of any records” responsive to our Open Records Request for any policy or protocol regarding the rationing of medical care or equipment.

In the absence of a state policy, individual hospitals and hospital systems are left to establish their own policies and protocols. It is imperative that these individual policies and protocols set forth procedures for making non-discriminatory determinations regarding the receipt of medical care and call for the formation of Ethics Committees to oversee the execution of these procedures. State guidance is necessary to ensure people with disabilities will not be automatically or prematurely deprioritized for medical care.

As you know, federal law prohibits discrimination against persons with disabilities. In the medical care setting, these laws include the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. Title II of the ADA prohibits state and local governments from discriminating against people with disabilities. Title III prohibits discrimination in places of public accommodation, such as hospitals, clinics, and doctor’s offices. Section 504 does the same for any recipient of federal funds and Section 1557 effects health care programs and activities who receive federal funds, including most private healthcare providers and insurance companies.

The Office for Civil Rights (OCR) recently issued COVID-19 specific guidance on March 28, 2020 which notes, “[P]ersons 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 individual assessment of the patient based on the best available objective medical evidence.”¹ Protection and Advocacy organizations, along with the ARC of the United States, and other interested parties have filed OCR complaints concerning policies in at least four states.

We ask the Commonwealth of Kentucky to issue guidance to hospitals and other healthcare providers regarding their obligations under the ADA and other federal disability non-discrimination laws to individuals with disabilities during all phases of treatment. This guidance should be public and should address both the allocation and

¹ The Guidance also provides suggestions on effective communication and meaningful access to programs and information to individuals with disabilities. These should also be followed; however, the focus of our letter today is access to ventilators and ICU beds.

continuation of medical treatment during this or any similar crisis. It should include the following criteria to avoid discriminatory outcomes:

1. Treatment allocation decisions must be based on individualized determinations, using current objective medical evidence. Treatment decisions should not be based on generalized assumptions about a person's disability, including the severity of the individual's disability.
2. Treatment allocation 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.
3. Treatment allocation 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 an allocation decision, 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.
4. Treatment allocation decisions cannot be based on the perception that a person's disability will require the use of greater treatment resources. Modifications must be made where needed to ensure persons with disabilities have equal opportunity to benefit from treatment.

Governor, your daily briefings have become a tremendous source of up-to-date information, compassion, and fellowship for Kentuckians. You have made a point to be as inclusive as possible of all Kentuckians, with Virginia Moore providing sign language interpretation being one of the more obvious measures. When the policy is created, we believe you, Dr. Stack, or Secretary Friedlander should include it in your daily briefing. This would have a tremendous impact on both providers and patients, and further minimize the risk that discrimination against the disabled in a medical setting will occur.

According to the Institute for Health Metrics and Evaluation, Kentucky will reach its "Peak Resource Use" on April 21, 2020. It is vital that Kentucky establish its protocols and communicate those to hospitals well before physicians and healthcare professionals make these heart-wrenching decisions. We understand that drafting this policy will require input from numerous groups, including the Kentucky Hospitals Association, the Kentucky Board of Emergency Medical Services, physicians, nurse practitioners, nurses, and bioethicists. The participation of the disability community, whose very lives are in peril if we all do not act, is imperative in the establishment of these protocols.

Due to the urgency of this matter, please let us hear from you by April 14, 2020.

Respectfully,



Jeff Edwards
Director

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Healthcare Equity
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A Disabled Activist
And A Civil Rights Worker

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Cc: Eric C. Friedlander, Secretary, Cabinet for Health and Family Services
Steven J. Stack, M.D., Commissioner, Department for Public Health.