

Alabama Withdraws Discriminatory Ventilator Rationing Policy and Issues Directive About Non-Discrimination in Accessing Life-Saving Treatment April 8, 2020

Today, in response to a complaint filed with the U.S. Department of Health and Human Services Office for Civil Rights (OCR) by the Alabama Disability Advocacy Program (ADAP) and other disability rights advocates, the state of Alabama has withdrawn its discriminatory ventilator rationing policy and instructed hospitals across the state that they cannot discriminate against people with disabilities in accessing treatment. The previous policy placed the lives of disabled adults and children at serious risk, in violation of federal law, by ordering hospitals to "not offer mechanical ventilator support for patients" with "severe or profound mental retardation," "moderate to severe dementia," and "severe traumatic brain injury." The complaint was filed by the ADAP and The Arc of the United States, together with counsel from the Center for Public Representation, Bazelon Center for Mental Health Law, and Sam Bagenstos.

After receiving the complaint, OCR took swift action to reach a resolution. With today's announcement, OCR has made clear to Alabama and states and hospitals across the country that excluding people with disabilities from access to life-saving treatment is illegal and intolerable.

"We are pleased that the state of Alabama has rescinded this illegal policy and given notice to hospitals across the state that they may not rely on this policy and cannot discriminate against people with disabilities in accessing lifesaving care," said Shira Wakschlag, Legal Counsel for the Arc of the United States. "States and hospitals across the country should heed OCR's warning and take affirmative steps to ensure their policies do not discriminate against people with disabilities," said Cathy Costanzo, Executive Director of the Center for Public Representation.

In addition to withdrawing the discriminatory policies, Alabama has put in place new Crisis Standards of Care (CSC) Guidelines that contain important nondiscrimination provisions. The new Guidelines do not, however, address how ventilators will be rationed in the event it becomes necessary to do so.

"Today's actions are an important first step, and we appreciate that the state of Alabama acted quickly to withdraw its discriminatory policy," said Rhonda Brownstein, Legal Director of the Alabama Disabilities Advocacy Program. "We call on the Governor to work with ADAP and others in the disability community to develop transparent and clear guidance on how to implement these nondiscrimination requirements in the event that rationing of ventilators becomes necessary."

Matthew Foster is an example of how Alabama's previous ventilator rationing policy could have impacted people with intellectual and cognitive disabilities. Matthew, who is 37-years-old and has Down syndrome, might have been excluded from access to a ventilator in the event under the previous policy. When Matthew was told that the state rescinded the discriminatory policy, he was relieved: "I have Down Syndrome. It's not going away. But I have a right to live. I'm worth it." Matthew, who has held a job for the past twenty years, has "had a positive impact on our family and community. The idea that his life is not worthy because of his intellectual disability is devastating and wrong," says his mother, Susan Ellis. "In this time of crisis, we cannot devalue the lives of others in our community based on their disabilities. It's morally wrong, and it violates the law. We are grateful that OCR acted quickly on the complaint and that the state of Alabama ended its previous policy. I can now breathe a sigh of relief."

ADAP and the other organizations involved in the OCR complaint will be vigilant in ensuring that hospitals across Alabama comply with the new non-discrimination requirements. "We will not hesitate to take further legal action if any discrimination against people with disabilities in accessing COVID-19 treatment occurs," said Jennifer Mathis of the Bazelon Center for Mental Health Law.

Complainants are represented by their counsel who are available for comment:

Rhonda Brownstein, Alabama Disabilities Advocacy Program

rbrownstein@adap.ua.edu

Shira Wakschlag, The Arc of the United States

Wakschlag@thearc.org

Jennifer Mathis, The Bazelon Center for Mental Health Law

jenniferm@bazelon.org

Cathy Costanzo and Alison Barkoff, Center for Public Representations

ccostanzo@cpr-ma.org; abarkoff@cpr-us.org

Samuel Bagenstos

sbagen@gmail.com