U.S. Civil Rights Office Rejects Rationing Medical Care Based on Disability, Age

Medical providers must not engage in “ruthless utilitarianism” in deciding who gets lifesaving treatment for the coronavirus, a federal civil rights officer warned.

“Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism,” said Roger Severino, the director of the Office for Civil Rights at the U.S. Department of Health and Human Services, in a news release on Saturday. Credit: Jacquelyn Martin/Associated Press

By Sheri Fink

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The director of the federal health department’s civil rights office said on Saturday that his office was opening a series of civil rights investigations to ensure that states did not allow medical providers to discriminate on the basis of disabilities, race, age or certain other factors when deciding who would receive lifesaving medical care during the coronavirus emergency.

The office released a new bulletin on civil rights during the coronavirus crisis, days after disability rights advocates filed complaints arguing that protocols to ration lifesaving medical care adopted by Alabama and Washington State were discriminatory.

“Our civil rights laws protect the equal dignity of every human life from ruthless utilitarianism,” Roger Severino, the office’s director, said in a news release. “Persons with disabilities, with limited English skills and older persons should not be put at the end of the line for health care during emergencies.”

Mr. Severino said in an interview that in response to multiple complaints, his office was opening the investigations to ensure that state-mandated rationing plans “are fully compliant with civil rights law.” He said his office had heard from “a broad spectrum of civil rights groups, pro-life
groups, disability rights groups, from prominent members of Congress from both sides of the aisle, from ordinary people who are concerned about their civil rights in this time of crisis.”

The bulletin “represents an important first step in protecting the rights of people with disabilities in the current crisis,” said Ari Ne’eman, a visiting scholar at the Lurie Institute for Disability Policy at Brandeis University and a senior research associate at the Harvard Law School Project on Disability. He said there was an “urgent need for comprehensive guidance.”

Many states and hospitals are developing plans for how to ration care if the number of critically ill coronavirus patients exceeds capacity. Patients who develop severe respiratory distress from coronavirus infection often require support from mechanical ventilators for days to weeks; the machines are expected to be in short supply in the United States. In Italy, doctors have had to make wrenching choices about who gets them and who does not. While attempts are made to increase production of new ventilators and to expand hospital capacity, these plans lay out who will get care if those efforts are not able to meet the need.

Many of the plans would prioritize patients who were most likely to survive their immediate illness, and who also had a better chance of long-term survival when taking other factors into consideration. Some assign patients a score based on calculations of their level of illness, with decisions between patients who have the same score made by random selection.

Some plans instruct hospitals not to offer mechanical ventilators to people above a certain age or with particular health conditions.

In Alabama’s plan, people with “severe or profound mental retardation” as well as “moderate to severe dementia” should be considered “unlikely candidates for ventilator support” during a period of rationing. Washington’s guidance recommends that triage teams consider transferring hospital patients with “loss of reserves in energy, physical ability, cognition and general health” to outpatient or palliative care.

Dr. Kathy Lofy, the health officer of Washington State, said in an email, “We are very concerned that people believe our scarce resource guidance might discriminate against people with disabilities so we are in the process of setting up time to meet with disability advocacy groups to discuss their concerns.”

“The guidance in Washington around managing scarce resources during emergencies was largely designed to avoid discrimination during the allocation of scarce resource and involves a regional team to ensure resources are being allocated in a fair way,” Dr. Lofy said.

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An emailed statement from the Alabama health department said that the state’s ventilator triage guidelines had been “greatly misunderstood” and were “solely intended as a tool for providers” making difficult choices. The statement said the document, which remained on its website on Saturday, was over a decade old and had since been replaced by a more comprehensive set of
guidelines for health care emergencies. Those newer guidelines did not address ventilator triage, but said that the allocation of care should not be discriminatory.

Dr. Doug White, who published a proposed framework for rationing critical care in the Journal of the American Medical Association on Friday, said in a webinar that it was important to have “triage guidelines that don’t exclude groups of patients.” He said a score-based approach, endorsed by Pennsylvania, would allow as many patients to be treated as possible, so that “if suddenly 1,000 new ventilators become available, nobody’s sitting without a ventilator.”

Still, some citizen groups who have looked at draft protocols expressed fears that even using predicted survival to determine who would get access to resources — the most common strategy — might be inherently discriminatory.

In a report of a community exercise held in Seattle, some participants said they were concerned that using the likelihood of survival as a rationing criterion was problematic because some groups, such as African-Americans and immigrants, might have poorer health as a result of “institutional racism in the health care system.”

The plans typically include protocols for removing ventilators from people after a certain time period if they do not appear to be improving. In some states, including New York, people who required ventilators long-term, such as those who have certain spinal cord injuries, could be subject to having their ventilators reassigned under the protocol if they were admitted to hospitals during the crisis.

Many of the plans, even if they do not include outright age restrictions, consider stage of life as a factor in assigning ventilators or critical care beds. The civil rights office’s new statement might put that into question.

Mr. Severino said that his office was not telling states how to allocate care, but that the bulletin “puts entities on notice that they need to start considering the civil rights implications of any crisis standards of care plans they may be putting into effect if it were to come to that.”

“It has to be part of the discussion,” he continued.

If the country reached a point where health care rationing standards would be applied, Mr. Severino said, “those standards must comply with civil rights laws.”

“Ultimately the question as to resource allocation is not a scientific or medical one,” he added. “It is ultimately a moral and legal one.”

The bulletin had an important new legal provision. It said that a March 17 declaration by the Secretary of Health and Human Services that provided immunity from legal liability to those developing or using “medical countermeasures” to fight the disease might also provide some immunity from civil rights claims.
Mr. Ne’eman said that finding was “deeply concerning,” adding that “enforcement of our civil rights laws should never be called into question, even in the context of an emergency.”

Mr. Severino said he was “unaware” of any time in which the federal health authorities had placed any limitations on civil rights laws during an emergency. He referred questions about the provision to the Office of the General Counsel, which did not immediately respond to a request to comment on it.

“I want to make sure in this time of crisis, we don’t forget the foundational principles that are part of what makes America so special,” Mr. Severino said. “That we do care for everybody, that every person in America deserves equal dignity and respect.”

He added, “Our response will be a reflection of our national character.”