

April 13, 2020

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, D.C. 20201

Roger Severino
Director
Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, D.C. 20201

Dear Secretary Azar and Director Severino:

The undersigned patient advocacy, aging network, family caregiver organizations, and other stakeholders write to urge you to ensure that, if the COVID-19 pandemic results in government decisions to ration treatment, that those decisions about how medical treatment is allocated are made without discriminating based on race, color, national origin, disability, age, sex, or exercise of conscience and religion.

In COVID-19 hotspots around the country, state health authorities are issuing rationing plans, anticipating that their healthcare systems will soon face scenarios of too many patients and not enough critical care equipment. Alabama's plan would restrict children and adults with intellectual and cognitive disabilities from getting ventilators. The Washington State Health Department suggests transferring patients out of the hospital or to palliative care if their baseline functioning is marked by "loss of reserves in energy, physical ability, cognition and general health."

Those decisions have relied on principles disadvantaging people with disabilities and older adults. While health care decisions inherently involve calculations based on risk and potential outcomes, they should never be based on the idea that it's more valuable to save a younger life than an older life, or a person who is disability-free than a person with a disability. Not only is it unethical, but little research has been done to see whether rationing strategies for COVID-19 would even save lives.

We were grateful to learn that the Office for Civil Rights (OCR) at the U.S Department of Health and Human Services is investigating whether state-mandated rationing plans comply with civil rights laws. We are also pleased to see OCR's bulletin to remind medical providers not to discriminate on the basis of disability, race, age or certain other factors when deciding who will receive lifesaving medical care.

While we praise OCR actions to date, we request that the office develop and release detailed guidance on how medical resources should be fairly allocated during the COVID-19 pandemic—as soon as possible. The guidance should be clear on what constitutes unlawful discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience and religion in HHS-funded programs as it relates to the allocation of limited resources due to the COVID-19 pandemic. This should include determinations concerning the denial, removal, or suspension of health care and services based on perceptions concerning "social worth", quality of life, life years remaining, or the intensity of services needed. OCR guidance should also remind all entities covered by civil rights authorities to keep in mind their obligations under all laws and regulations that prohibit discrimination including the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794), the Age Discrimination Act of 1975 (42 U.S.C. 6101 et

seq.), or section 1557 of the Patient Protection and Affordable Care Act (42 U.S.C. 18116) in the allocation of health care resources.

To be clear, covered entities should be permitted to prioritize those with a greater urgency of need and delay non-urgent care. They need not allocate scarce resources to individuals with no chance of survival. But *no* person should face discrimination in seeking life-sustaining care that they will benefit from. The lives of all people are equally valuable, and healthcare decisions that devalue the lives of people based on their race, color, national origin, disability, age, sex, or exercise of conscience and religion, are discriminatory.

The United States has long been a leader in many aspects of health care, accessibility, and civil rights protections. We would welcome the opportunity to work with you and your staff to ensure that all people receive equal and effective health care during the COVID-19 crisis under the priorities detailed above. Please contact Sue Peschin, President and CEO at the Alliance for Aging Research, at speschin@agingresearch.org with questions or to arrange further dialogue with the undersigned organizations.

Sincerely,

ADAPT of Texas
Aging Life Care Association
Alliance for Aging Research
Alzheimer's Foundation of America
American Academy of Physical Medicine & Rehabilitation
American Association for Geriatric Psychiatry
American Association on Health and Disability
American Council of the Blind
American Diabetes Association
American Geriatrics Society
American Kidney Fund
American Society of Consultant Pharmacists
Arthritis Foundation
CancerCare
Cancer Support Community
Caregiver Action Network
Center for Public Representation
Community Catalyst
Diabetes Patient Advocacy Coalition (DPAC)
Disability Rights Education and Defense Fund (DREDF)
GO2 Foundation for Lung Cancer
HealthyWomen
International Association for Indigenous Aging
Justice in Aging
Lakeshore Foundation
LEAD Coalition (Leaders Engaged on Alzheimer's Disease)
Men's Health Network

National Adult Protective Services Association
National Alliance for Caregiving
National Asian Pacific Center on Aging (NAPCA)
National Association of Area Agencies on Aging
National Association of Councils on Developmental Disabilities
National Association of Social Workers
National Association of State Directors of Developmental Disabilities Services
National Consumers League
National Diabetes Volunteer Leadership Council
National Health Council
National Hispanic Council on Aging
Partnership to Fight Chronic Disease
Prevent Blindness
Research!America
RetireSafe
The Gerontological Society of America
The Jewish Federations of North America
The Mended Hearts, Inc
WomenHeart: The National Coalition for Women with Heart Disease