April 22, 2020

Via Electronic Mail

The Honorable Gavin Newsom
California State Capitol
1303 10th Street, Suite 1173
Sacramento, California 95814

Mark Ghaly, M.D.
Secretary, Health and Human Services Agency
California Health and Human Services
1600 Ninth Street, Room 460
Sacramento, CA 95814

Dear Governor Newsom and Secretary Ghaly:

We are organizations and networks representing tens of thousands of Californians with disabilities and chronic medical conditions. We write with urgency and concern regarding the California health care rationing guidelines published on April 19, 2020. *See* SARS-CoV-2 Pandemic: Health Care Surge Crisis Care Guidelines, Concept of Operations (Apr. 2020), at https://www.cdph.ca.gov/Programs/CID/DCDC/CDPH%20Document%20Library/COVID-19/California%20SARS-CoV-2%20Crisis%20Care%20Guidelines4-20.pdf.

Rationing guidelines, also known as "Crisis Standards of Care," justify their deviation from normal standards of patient care on the basis of community well-being and need. Yet the community – including disabled persons, older adults, people of color, LGBTQ+ persons, and their families – was not consulted during the development of these guidelines. They were issued without input from disability rights organizations or advocates, despite weeks of outreach on this issue.[1]

The lives of people with disabilities are equally worthy and valuable as those of people without disabilities. Under state and federal laws, people with disabilities must have an equal opportunity to receive life-sustaining treatment during the COVID-19 pandemic. But the California rationing policy as written:

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[1] On March 20, 2020, DREDF sent a letter to Governor Newsom raising its concerns with disability-based medical rationing, and stressing the need for enhanced home and community-based services that would enable disabled and older people to stay safe at home and avoid hospitalization. And on April 3, 2020, Justice in Aging, DREDF, and Disability Rights California joined a letter to the California Health and Human Services Agency requesting stronger state guidance against discrimination on the basis of age in medical rationing. *See* Disability Rights Education and Defense Fund, COVID-19 Advocacy & Resources, at https://dredf.org/covid-19-advocacy-and-resources/. And earlier today, Justice in Aging, DREDF, Disability Rights California, and others sent a letter urging immediate action to eliminate age discrimination from the guidelines.

- Directs the denial of care to disabled individuals who could benefit from treatment and survive hospitalization; and

- Amplifies the impact of historic and systemic discrimination in health care, disproportionately affecting already marginalized groups, including not only disabled people but people of color, older people, and higher weight individuals.

People with disabilities already face pervasive negative biases and inaccurate assumptions among medical professionals about their quality of life.[2] During COVID-19, these biases can have serious and even deadly consequences.

California's policy will have long-lasting consequences, well beyond the current crisis, and regardless of whether or to what extent California experiences health care rationing. Rationing policies do more than just advise hospitals and health care providers. They communicate the views of the medical establishment and government agencies about disabled people and older adults. The views contained in these policies will be there, and will linger, long after the COVID-19 crisis is over.

We call on the State of California to reject disability discrimination in the allocation of scarce resources during COVID-19.

<u>No Commitment to Disability Nondiscrimination and Reasonable Modifications</u>.

Nowhere does the policy express a commitment to the principles of disability rights or the implementation of necessary safeguards against discrimination. There is no reference to the reasonable modifications that disabled people might need to have an equal chance to access life-saving care. The guidelines repeatedly emphasize necessary training of triage staff, *see* Guidelines, at pp. 3, 8-11, but do not reference the need to train about civil rights and disability nondiscrimination. The only reference to nondiscrimination <u>*excludes*</u> reference to disability and age. *See* Appendix A, at p. 3 ("Regardless of who communicates the decision, it may be useful to explain the medical factors that informed the decision, as well as the factors that were not relevant (e.g., race, ethnicity, gender, insurance status, perceptions of social worth, immigration status, etc.).").

There is nothing in the policy that guides triage leadership on how to ensure that health disparities and inequities already impacting certain communities of color and other marginalized groups including higher weight people are not used to justify further

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[2] See National Council on Disability, "Federal study finds rampant bias in medical 'futile care' decisions" (Nov. 20, 2019), at https://ncd.gov/newsroom/2019/NCD-study-medical-futility; Bioethics and Disability Report Series, at https://www.ncd.gov/publications/2019/bioethics-report-series.

discrimination.[3] Many studies over decades establish the many barriers that routinely subject disabled people to less effective care.

It is critical that any guidelines for health care rationing both articulate and closely follow principles of equity and nondiscrimination, including explicit protections on the basis of disability. Any recommendations for training of triage staff should include the principles of disability nondiscrimination, the need for accessibility, reasonable accommodations, and policy modifications, and the importance of challenging explicit and implicit bias among medical professionals related to disability, race, ethnicity, weight, age, and other personal characteristics. We also strongly recommend that triage leadership and review teams include medical professionals, such as physiatrists, who have long-term practical experience working with people with significant disabilities, as well as community representatives.

“Life Expectancy,” “Long-Term Survival,” and “Life Years”

In Appendix A, the California rationing guidelines state that one of two guiding principles in the allocation of scarce resources such as ventilators is “saving the most life-years.” Appendix A at p. 5. Accordingly, “[p]atients who do not have serious comorbid illness are given priority over those who have illnesses that limit their life expectancy.” *Id.* The guidelines set out a scoring system for triage that weighs “prognosis for long-term survival.” *Id.* at pp. 5-6, tables 2-3. The document gives examples of “comorbidities” associated with shorter life expectancy, and for which additional points should be assigned (the higher the points, the lower the priority for care), but emphasizes that additional conditions can trigger points. *Id.* at 6 (“*This Table only provides examples. There are likely other reasonable approaches to designating 0, 2, or 4 points according to the ‘save the most life-years’ principle.”).

The use of life expectancy, long-term survival, or “life years” as a basis for exclusion from, or lower priority for, treatment during COVID-19 discriminates against people with disabilities who have or who are thought to have a shortened life expectancy due to their disabilities. Such individuals include people with cystic fibrosis, spinal muscular atrophy, ALS, Down Syndrome, other intellectual and developmental disabilities, HIV/AIDS, kidney disease, and metastatic cancer, as well as higher weight people. People with these and other disabilities regularly outlive the estimated prognoses that doctors ascribe to them. **Moreover, having disability diversity is valuable and essential to our society, even if some people with disabilities do not live as long** as their non-disabled peers**.** People with disabilities make unique contributions – including to developing the systems of care we need during a public health crisis.

The American College of Physicians recognized this in their March 26, 2020 resolution, which states: “Allocation of treatments must maximize the number of patients who will recover, not the number of “life-years,” which is inherently biased against the elderly

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[3] *See* Harald Schmidt, “The Way We Ration Ventilators Is Biased: Not every patient has a fair chance.” New York Times (Apr. 15, 2020), at https://www.nytimes.com/2020/04/15/opinion/covid-ventilator-rationing-blacks.html.

and the disabled." American College of Physicians, Non-Discrimination in the Stewardship and Allocation of Resources During Health System Catastrophes Including COVID-19, at https://www.acponline.org/acp_policy/policies/acp_policy_on_non-discrimination_in_the_stewardship_of_healthcare_resources_in_health_system_catastrophes_including_covid-19_2020.pdf.

The use of life expectancy and "life years" as a basis for allocating scarce resources such as ventilators during COVID-19 is an impermissible form of disability discrimination. Prognoses about remaining life years are inherently speculative and based on averages derived from historical studies, potentially discounting recent advances in healthcare and, just as importantly, importing discriminatory recruitment of research subjects and lifetime differences in health care quality received by subjects within those studies. It is critical that any guidelines about allocating scarce resources during the pandemic direct an individualized assessment of whether the person can benefit from care and survive hospitalization. Such guidelines must not consider survival beyond the immediate short term.

Reliance on "Comorbidities" to Assess "Long-Term Survival"

The California guidelines describe a scoring system for triage that weighs "long-term survival" due to "comorbidities." *Id.* at 5-6. Patients get points – and therefore a lower priority for treatment – for "comorbidities" deemed to indicate fewer "life years" or life expectancy. The document gives examples of such conditions, which include: moderate dementia; cancer with less than ten year expected survival; COPD; end-stage renal disease; certain forms of heart disease; and cirrhosis. The document also advises that additional conditions may support an allocation of negative points, so long as the assessment advances the principle of "life years."[4]

The listed and unlisted "comorbidities" are disabilities protected under state and federal laws. The fact that a patient has a particular diagnosis is not a permitted reason for denying care or making that person a lower priority to receive treatment. Doctors must make an individualized assessment of whether the person can benefit from care and survive in the immediate short term. They must not assume that any specific diagnosis or disability automatically indicates a poor prognosis for near-term survival or an inability to respond to and benefit from treatment.

In some cases, valid prognostic data will not be available to determine whether a patient has a condition that significantly limits near-term prognosis. In such cases, when prognosis is uncertain, triage officers should not assign points based on the patient's underlying, baseline conditions. The mere existence of certain underlying medical conditions should not be used in and of themselves to assign points, unless there is objective medical evidence that the condition significantly limits near-term survival for the particular patient.

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[4] The Elixhauser Comorbidity Index referenced in the document as another source for assessing "life years" includes such conditions as HIV/AIDS, paralysis, obesity, and depression.

It is critical that any guidelines adopted to allocate scarce resources do not disadvantage individuals with particular diagnoses who can benefit from treatment and survive. All people with disabilities are entitled to receive lifesaving care, unless it is medically clear that the person will not survive in the immediate term or that the treatment is contraindicated.

Assessments Based on SOFA Scores

The California Guidelines describe a scoring system for triage that includes short-term prognosis based on SOFA (Sequential Organ Failure Assessment) scores. *Id.* at 5-6. SOFA scores may discriminate on the basis of disability where a patient starts with a higher score due to a pre-existing stable "baseline" disability unrelated to the current need for acute care, such as a chronic condition requiring daily ventilator use. Baseline conditions should not increase SOFA scores for purposes of any rationing scheme unless those conditions directly impact an individual's short-term survivability with treatment.

Further, components of the SOFA assessment may misconstrue disability-related characteristics. For example, the Glasgow Coma Scale, a tool for measuring acute brain injury severity, adds points to the SOFA score when a patient cannot articulate intelligible words, even if this condition is due to a pre-existing speech disability or chronic ventilation. Where accurate completion of one or more components of the SOFA is not possible due to a disability unrelated to the acute condition being assessed, the patient should not be scored on the component(s) and should not receive negative points.

It is critical that any guidelines endorsing a scoring system like the SOFA include reasonable modifications to ensure that the score reflects an objective assessment of whether an individual can benefit from treatment and survive in the short term.

In addition, the use of the SOFA or similar tools should also be reassessed throughout the pandemic. The SOFA was developed for assessing prognosis for patients who experience sequential organ failure from the underlying disease of sepsis. We do not know yet how well it predicts outcomes in the COVID-19 context or for people with particular chronic diseases or disabilities.

Trials and "Reallocation" of Ventilators

The California guidelines discuss the reassessment of patients on ventilators after a therapeutic trial, and the "reallocation" of ventilators for patients who do not show improvement. *Id.* at 9-10.

Such a reallocation policy has a chilling effect on individuals with disabilities who utilize ventilators in their daily lives. Regular users of ventilators are afraid to seek medical help when they become ill because ventilator rationing may result in their every-day ventilators being reallocated to other patients who are deemed a higher priority, with the result being death. The “reallocation strategy” in the California guidelines explicitly references the potential for this occurring not only in an actual shortage of equipment, but “in anticipation of a shortage.” Guidelines, at p. 8.

It is critical that any rationing guidelines discussing the reallocation of medical equipment make clear that doctors and triage teams may not “reallocate” the personal ventilators or other equipment of disabled patients who rely on this equipment regularly. These patients are entitled to continue to use their personal (rented or owned) equipment if they receive COVID-19 treatment at a hospital. This equipment is personally calibrated and as necessary to an individual’s well-being as a prosthetic limb or an organ.

Moreover, hospitals and other health care providers are required to make reasonable modifications in policies, practices, and procedures when needed by a disabled person to have an equal opportunity to benefit from the treatment. Some individuals may need a longer therapeutic trial on a ventilator to show improvement because of disability. Any guidelines setting out time intervals for ventilator assessment and reallocation should include the provision of a longer period of time as a form of reasonable modification for disability.

The language in the guidelines is contrary to the possibility of a reasonable modification in the duration of the ventilator trial. *See* Appendix A at pp. 3-4 (“Appeals [on withdrawing scarce care] based in an objection to the overall allocation framework should not be granted.”).”). The guidelines should make clear that hospitals may be required to grant reasonable modifications to disabled patients, including with respect to ventilator trials.

Prevention of Rationing

Hospital systems in California are deeply siloed based on payment source. While there are some requirements to cover patients for “out of network” emergency room visits, there is little experience among the separate health care systems to coordinate and plan collectively in response to shortages such as those posed by COVID-19.

The guidelines should direct California’s accredited hospitals and hospital systems to coordinate by sharing real-time information about ventilator and ICU availability on a geographic basis. In this way shortages of equipment, space, or personnel at a single hospital can be alleviated through transfers to another ICU location. No disabled, older, or higher weight patient should be triaged out of care when a ventilator is available a couple of blocks away, even if the other hospital has a different owner or is out-of-network. (And if this coordination is already in place through the efforts of California and medical stakeholders, then we seek an update on such important measures.)

Priority for Individuals Who Perform Tasks Supporting Acute Care

The California Guidelines recommend that priority should be given to workers who support the provision of acute care to others during the pandemic. *Id.* at 7. We believe that if this type of priority is adopted, then individuals who keep disabled individuals safe in their homes, including personal care attendants and home health care providers, should also be given priority. These essential workers help keep disabled people away from the hospital and the prospect of health care rationing.

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We urge you to act immediately to center the interests and needs of the disability community in responding to COVID-19. It is critical that any guidelines or policies for the allocation of scarce resources in California during COVID-19 focus on the ability to benefit from and survive treatment, rather than on traits and statuses that are proxies for disability.

The California medical rationing guidelines should be suspended until there is a genuine opportunity for inclusion of patient voices, specifically including input from disabled representatives and advocates as well as people of color, higher weight individuals, and aging communities. Community decisions cannot be made solely on the basis of medical expertise.

California's admirable leadership in ordering all residents to shelter in place is for naught if its rationing guidelines discourage disabled, older, or higher weight persons, or people of color, from going to hospitals out of fear that their own equipment may be taken away, or that others deemed to have greater life years ahead of them will be granted a higher priority to life-saving care.

To discuss these concerns further, please contact Claudia Center at 415-531-2874 who can set up a meeting with community representatives.

Sincerely,

Claudia Center
Legal Director
Disability Rights Education and Defense Fund

Organizational Sign-Ons:

Disability Rights Education and Defense Fund

Disability Rights California

#NoBodyIsDisposable Coalition

Justice in Aging

Senior & Disability Action

APLA Health

California Alliance for Retired Americans

California Council of the Blind

Cancer Legal Resource Center

Congress of California Seniors

Cystic Fibrosis Research, Inc.

Disability Rights Advocates

Disability Rights Legal Center

FLARE Project (Fat Legal Advocacy, Rights, and Education)

Fat Rose

Mental Health Advocacy Services

The Myalgic Encephalomyelitis Action Network

National Center for Lesbian Rights

National Multiple Sclerosis Society

The Salvador E. Alvarez Institute for Non-Violence

San Francisco AIDS Foundation

San Francisco Community Health Center

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