DISABILITY RIGHTS
PENNSYLVANIA

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BY EMAIL

Ray Barishansky
Deputy Secretary for Health Preparedness
and Community Protection
Pennsylvania Department of Health
Health & Welfare Building, 8th Floor West
625 Forster Street
Harrisburg, PA 17120
rbarishans@pa.gov

Re: *Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines*

Dear Mr. Barishansky:

In response to Secretary Levine's March 31, 2020 letter, Disability Rights Pennsylvania (DRP), the organization designated by the Commonwealth pursuant to federal law to protect the rights of and advocate for people with disabilities, submits these comments on the latest draft of the Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines ("PA Guidelines"). DRP is joined in these comments by Achieva; ARC of Greater Pittsburgh; The ARC of Pennsylvania; Center for Advocacy for the Rights and Interests of Elderly (CARIE); The Coalition for Inclusive Community; Institute on Disabilities, Temple University; NAMI Keystone PA; Parents Exchange; and the Pennsylvania Council on Independent Living.

DRP and a group of disability advocacy organizations from across Pennsylvania filed a complaint with the United States Department of Health and Human Services' Office of Civil Rights (OCR) last week asserting that

the prior version of the PA Guidelines violated Title II of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (RA), and Section 1557 of the Patient Protection and Affordable Care Act (ACA). A copy of that Complaint is attached. Unfortunately, the revised PA Guidelines include essentially the same unlawful provisions as the prior version and, indeed, may have a greater discriminatory impact on individuals with disabilities.

A. Use of Prognosis

One of the core tenets of those federal non-discrimination laws is that decisions by covered entities must be based on individualized determinations using objective evidence rather than assumptions, stereotypes, and myths about people with disabilities. Indeed, as OCR stated in its recent Bulletin, federal disability rights laws "protect the equal dignity of every human life from ruthless utilitarianism." OCR, *Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-2019)* at 2 (Mar. 28, 2020), https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf

The overarching framework of the PA Guidelines is grounded in an explicit rejection of this tenet. A utilitarian approach is embraced throughout:

- "Medical care shifts from focus on individuals to promoting the thoughtful use of limited resources for the best possible health outcomes for the population as a whole." PA Guidelines at 11.

- "Under the Crisis Standard of Care Guidelines, the focus of medical care may shift from the individual patient to promoting the thoughtful use of limited resources for the best possible health outcome of the population as a whole." PA Guidelines at 25.

- "The primary goal of the allocation framework is to maximize benefit to populations of patients, often expressed as doing the greatest good for the greatest number. This allocation framework is based primarily on two considerations: 1) saving the most lives; and 2) saving the most life years." PA Guidelines at 30.

- The Patient Evaluation Tool to Allocate Critical Care allocates up to four points to patients based on an assessment of their short term survival under the principle of "saving the most lives," and allocates up to four points to patients based on an assessment of their long term prognosis under the principle of "saving the most life years." PA Guidelines at 30, Table 1.

While a focus on saving the most lives appears laudable, it begs the question how it is decided which lives will be lost. Under the PA Guidelines, people with disabilities would be put at the end of the line for critical care. Pennsylvanians with disabilities should not bear the brunt of medical rationing during this crisis. The Department of Health has a legal obligation to issue triage guidelines that affirmatively safeguard against discrimination against people with disabilities, and the PA Guidelines fall short.

All persons should be eligible for, and qualified to receive, lifesaving critical care regardless of the presence of an underlying disability or co-morbid conditions, unless it is clear that the person will not survive in the immediate term or the treatment is contra-indicated. The principle of saving the most lives must conform to this to avoid discrimination against people with disabilities.

The PA Guidelines aim to save the most lives by assigning patients points based on evaluation under a tool called the Sequential Organ Failure Assessment (SOFA). SOFA standards are discriminatory as people with disabilities may start with a higher baseline score due to pre-existing conditions. People with chronic conditions requiring daily ventilator use are penalized for their pre-existing disabilities and are assigned a higher SOFA score as a result of their baseline condition. Similarly troubling, another component of SOFA requires assessment of acute brain injury function under which a person with a speech disability could receive a two-point SOFA penalty despite the fact that the speech impediment does not impact short-term prognosis. The PA Guidelines must eliminate this built-in bias against people with disabilities that de-prioritizes them for life-saving medical care.

Turning to the principle of saving the most life years, such considerations of long-term prognoses are inherently problematic. The PA Guidelines incorporate discrimination explicitly into the triage criteria, stating "[p]atients who do not have serious comorbid illness are given priority over those who have illnesses that limit their life expectancy." PA Guidelines at 30.

Specifically, patients with conditions deemed to be severely life-limiting are awarded a disqualifying four points (as status in the group receiving critical care is only given to patients with one to three points). Patients with conditions deemed to be major comorbidities are awarded two points, which, even with a relatively good prognosis for short-term hospital survival, effectively disqualifies most of these patients from the group receiving critical care as well. Consideration of long-term prognosis are discriminatory in that these patients are all individuals with disabilities who will largely, if not completely, be screened out of care.

Further, considerations of life expectancy over the longer term are discriminatory in that those determinations are rife with bias. Doctors associate certain disabilities with a poor prognosis for long-term survival even though people with disabilities regularly outlive the prognoses that doctors ascribe to them, often by years:

> Bias does not just affect judgments about the quality of life with a disability. It also renders suspect judgments about disabled persons' expected length of life. Studies have repeatedly demonstrated that physicians maintain (conscious or unconscious) bias about disability, as detailed in the National Council on Disability's latest bioethics and disability report series to policymakers. Such bias can lead them to underestimate disabled patients' life expectancy. Even if, in the abstract, doctors could ethically rely on expected length of life — and, again, would we permit them to deny lifesaving treatments to members of racial minority groups if the actuarial tables demonstrated that members of those groups live shorter lives? — their concrete judgments about the effect of disability on life expectancy are likely to be unreliable.

Neil Romano and Samuel Bagenstos, "Don't Deny Ventilators to Disabled Patients," Washington Post (April 6, 2020). "[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." *Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-2019)* at 1.

B. Withdrawal of Care

As delineated in our Complaint, the ADA, RA, and ACA all require that covered entities make reasonable modifications to their policies, practices, and procedures when necessary to avoid discrimination. That includes permitting a person to continue using a ventilator for additional time where an underlying disability means that additional time is necessary for ensuring an equal opportunity for the person with a disability to benefit from the treatment. The PA Guidelines fail to incorporate this principle and, indeed, potentially permit its violation by allowing critical care to be withdrawn from patients – even before the end of the established therapeutic trial period. Patients with underlying disabilities may well require longer time on a ventilator for treatment to be effective than those without such disabilities. Failure to allow longer use of ventilators for individuals whose disabilities require it violates the reasonable modification mandate.

The PA Guidelines also allow doctors to use their "overall clinical judgment" to justify withdrawal of care. This permits implicit bias and quality- of-life considerations to taint decision-making, leading to discrimination against people with disabilities.

The PA Guidelines' withdrawal of care guidelines implicitly allows triage officers to withdraw ventilator care from an individual who came to the hospital with the ventilator she or he uses in daily life. People who are dependent on ventilators should not be at risk of losing their life-preserving equipment if they must go to the hospital. Failure to include such protections in the Guidelines will discourage such individuals from seeking necessary health care – for COVID-19 or any other issues that may require hospitalization.

C. Failure to Require Review and Oversight

The PA Guidelines fail to provide for any review of the triage officer's or team's decisions, including decisions to withdraw care. Nor do the PA Guidelines provide for maintaining centralized, consistent information relating to triage decisions for assessment of potential areas of concern. It is important to include both the opportunity for review and for oversight of any prioritization decisions and withdrawal of care.

A review committee should review all decisions of the triage officer or team. The committee should consult with specialists if necessary (e.g., with a pulmonologist if the patient has lung disease). The committee should assess whether the triage officer/team considered all clinical information and accurately documented its decision. The committee should be empowered to overturn decisions that do not comport with objective medical evidence. A patient's physician or family should also be able to seek review of a decision, particularly for withdrawal of care, from a health care professional (outside the review committee) and ethicist.

Finally, each hospital must track triage data, including patient demographics (e.g. all conditions, illnesses, diseases, disabilities other than COVID-19), date and time of case consideration, triage officer's/team's decision, supporting documentation reviewed, and all changes in status, including withdrawal of treatment.

D. Recommendations

DRP requests the opportunity to discuss the PA Guidelines and how to revise them to protect individuals with disabilities against unlawful discrimination with appropriate decision-makers. At this time, we would recommend at least the following:

- The PA Guidelines should expressly incorporate important non-discrimination principles contained in OCR's Bulletin as well as in the document endorsed by national disability rights organizations from across the country, *Applying HHS's Guidance for States and Health Care Providers on Avoiding Disability-Based Discrimination in Treatment Rationing,* https://www.centerforpublicrep.org/wp-

content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf, including, at minimum:

  - statements that health care providers are bound by federal non-discrimination laws, that they must respect the value and dignity of people with disabilities, and that people with disabilities must have an equal opportunity to receive critical care;
  - reminders to health care providers to guard against possible biases;
  - a prohibition against consideration of quality of life judgments in assessing whether to provide or withdraw care;
  - a requirement that health care providers assure that all treatment decisions are based on objective criteria, rather than assumptions, stereotypes, or myths;
  - requirements that health care providers provide effective communication to patients and family members who are deaf, hard of hearing, blind, have low vision, or have speech disabilities to maximize the patient's ability to participate in his or her care and to avoid physicians substituting misplaced assumptions and biases;
  - requirements that health care providers provide effective communication for those with sensory disabilities or cognitive disabilities, including intellectual disability, by allowing the presence at all times of a "communicator" to help the individual understand what is happening and to help them express their needs and assuring that the communicator receives any necessary personal protective equipment to prevent spread of infection.

- The PA Guidelines should eliminate consideration of long-term survivability based on the presence of preexisting disabilities.
- The PA Guidelines should not permit use of prognosis in determining whether to provide health care where based on objective medical evidence the patient would survive in the immediate term with appropriate critical care treatment.

- The PA Guidelines must make reasonable modifications to allow individuals whose underlying disabilities require longer treatment to receive such treatment.
- The PA Guidelines should prohibit health care providers from reallocating ventilators that patients use in their daily life and bring with them to the hospital.
- The PA Guidelines should incorporate review and oversight protections.

We appreciate your consideration of these comments. If you have questions, please contact me at 215-238-8070 x221 or kdarr@disabilityrightspa.org. We look forward to discussing these concerns with appropriate decision makers.

Sincerely,

Kelly Darr
Legal Director

Enclosure

cc: Kevin Hoffman, Esq. kjhoffman@pa.gov