DISABILITY RIGHTS
PENNSYLVANIA

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April 15, 2020

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

Re: Second Supplement to Complaint of Disability Rights Pennsylvania concerning Pennsylvania's Interim Crisis Standards of Care for Pandemic Guidelines

Dear Mr. Severino:

On April 3, 2020, Disability Rights Pennsylvania (DRP) submitted a Complaint to the Office for Civil Rights (OCR) on behalf of itself and other disability organizations, asserting that Pennsylvania's health care rationing system, titled "Interim Pennsylvania Crisis Standards of Care for Pandemic Guidelines" (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).

Subsequently, the Pennsylvania Department of Health (DOH) issued a revised draft of the PA Guidelines (Revised PA Guidelines). On April 7, 2020, DRP wrote to DOH, explaining that the Revised PA Guidelines included substantially similar unlawful and discriminatory provisions as the prior version and filed those comments with OCR as a supplement to its Complaint. On April 9, 2020, at DOH's invitation, DRP edited the Revised PA Guidelines to include essential language to protect people with disabilities from discrimination and submitted the edited document to DOH

On April 13, 2020, DOH issued "Version 2" of the PA Guidelines dated April 10, 2020 (April 10 Guidelines), a copy of which is submitted with this

Second Supplement). While DOH incorporated some non-discrimination principles into the April 10 PA Guidelines -- including language requiring individualized assessments based on objective medical evidence (pages 29, 30), cautioning against denying care based on stereotypes and quality of life judgments (page 29), and prohibiting confiscation of adults' personal ventilators (page 34) – the April 10 Guidelines remain unlawfully discriminatory.[1]

DRP and the other complainants incorporate by reference its April 3 Complaint and April 7 Supplement, and submits this Second Supplement to highlight the ways in which the April 10 Guidelines continue to violate federal disability rights laws.

A. Use of Life Years to Prioritize Patients

DOH uses a point system to categorize patients into color-coded priority groups. Points are assigned using a two-step evaluation tool. In the first step, patients receive a score of 1 to 4 points based on prognosis for short-term survival using the Sequential Organ Failure Assessment (SOFA) score or other validated measurement to assess the probability of surviving treatment for the acute critical illness. In the second step, which DOH describes as designed to "save the most life years," patients receive an additional 2 points or 4 points based on underlying disabilities. Patients receive 2 points if they have "major underlying conditions that limit near-term prognosis; death likely within 5 years." Patients receive 4 points if they have severely life-limiting conditions likely to result in death within one year. Lower total points correlate to higher priority for scarce medical resources. Patients who score 1 to 3 points on the 8-point scale will be placed in the red group, which is the highest priority. April 10 Guidelines at 31.

DOH's evaluation tool continues to unlawfully penalize people with disabilities. Adding points for underlying disabilities excludes individuals with disabilities from access to treatment for COVID-19. Only individuals

[1] The discriminatory components of the April10 Guidelines as they relate to adults are equally discriminatory as they relate to pediatric patients. Importantly, by way of distinction, although the April 10 guidelines prohibit reallocation of an adult patient's personal ventilator, the same prohibition is not included for children.

with pre-existing disabilities will receive additional points. Those with disabilities deemed to be "major" and likely causing death within five years will earn two points which, even if they have a relatively good prognosis for surviving the acute critical illness under step one, will almost certainly result in disqualification from the highest priority group. Accordingly, step 2 of the evaluation tool excludes or tends to exclude individuals with disabilities, which violates the ADA and RA. *See* Complaint at 4, 6-7.

DOH's exclusion based on life expectancy unrelated to surviving the acute critical illness is particularly troubling because it fails to account for the uncertainty surrounding longer-term survival probabilities. Many patients outlive near-term survival predictions, often significantly so. In addition, medical innovations and other interventions can improve a person's long-term prognosis. Finally, doctors' biases can lead them to associate certain disabilities with a poor prognosis for survival.

> 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), https://www.washingtonpost.com/outlook/2020/04/06/coronavirus-ventilators-disabled-people/.

Not only is use of life-years unlawfully discriminatory, it is also unnecessary for an effective rationing policy that aims to save the most lives. Arizona has adopted standards that assess only a patient's immediate-term survivability, *i.e.*, whether treatment will enable them to recover from COVID-19 or the other acute illness that requires critical care. Arizona does not discriminate against those with underlying disabilities that may limit "life years." *See Arizona Crisis Standards of Care Plan* at 30-31 (3d ed. 2020), https://www.azdhs.gov/documents/preparedness/emergency-preparedness/response-plans/azcsc-plan.pdf.

In the April 10 Guidelines, DOH asserts that when allocating scarce medical resources "[t]here is precedent for" for allocating points to, and, therefore, de-prioritizing patients with disabilities that are judged to impact near-term prognosis (e.g. "death likely within 5 years"). April 10 Guidelines at 30. DOH misses the mark.

First, DOH observes that "[t]he American Medical Association guidance on allocating scarce resources includes duration of benefit as a valid criterion." The American Medical Association encourages physicians to advocate for rationing policies that allocate resources "fairly among patients" that consider a number of factors, including "likelihood and anticipated duration of benefit." American Medication Association, "Allocating Limited Health Care Resources," Code of Medical Ethics Opinion 11.1.3, https://www.ama-assn.org/delivering-care/ethics/allocating-limited-health-care-resources. The American Medical Association does not, however, expressly or implicitly endorse consideration "duration of benefit" beyond immediate-term survivability of the acute illness for which critical care is needed or, for that matter, any specific timeframe. No support is noted for maximizing life years, and certainly not for docking patients who have a life expectancy of 5 years.

Notably, the American College of Physicians has recently rejected use of life-years in allocating health care resources, writing:

> [R]esource allocation decisions should be made based on patient need, prognosis (determined by objective scientific

> measures and informed clinical judgment) and effectiveness (i.e., the likelihood that the therapy will help the patient recover). **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 and the disabled**.

American College of Physicians, *Non-Discrimination in the Stewardship and Allocation of Resources During Health System Catastrophes Including COVID-19* (Mar. 26, 2020) (emphasis added), 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.

Second, DOH points to "[f]rameworks for allocation of organs for transplantation, which is overseen by the U.S, Department of Health and Human Services," that "include near-term duration of benefit as a criterion. (e.g., the Lung Allocation Score)." The referenced policy for allocation of lungs considers post-transplant survival as measured by the number of days the patient will likely survive in the first year. Organ Procurement and Transplantation Network, Policy 10, at 220, https://optn.transplant.hrsa.gov/media/1200/optn_policies.pdf. This is very different from considering conditions deemed to cause death within five-years of successful critical care treatment for an acute illness.

Finally, DOH cites the National Council on Disability's study of discrimination in organ transplants because "it did not recommend against duration of benefit as a criterion." The lack of a specific recommendation against consideration of "duration of benefit" cannot be construed as an endorsement of consideration duration of benefit over an extended period of time (such as five years). More significantly, in the context of organ transplantation, the Council stated that **"disability should only be taken into account to the extent that it can be clearly shown to be likely to impair successful transplantation."** National Council on Disability, Organ Transplant Discrimination Against People with Disabilities, at 14, 66 (Sept. 25, 2019),

https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf (emphasis added). This recommendation fails supports the principle that consideration of "duration of benefit" beyond recovery for acute critical illness is inappropriate, contrary to DOH's assertion.

B. Failure to Reasonably Modify SOFA

As noted above, step one of the evaluation tool assigns points based on an assessment of the patient's survivability of the critical acute illness represented by the patient's SOFA score. While assessing the likelihood of survival with treatment for COVID-19 may be a reasonable and fair basis to ration health care, it is still imperative that the assessment tool be non-discriminatory and not be administered in a discriminatory manner. For the reasons set forth in our first Supplement, DOH must make clear that health care providers are obligation to make reasonable modifications to the application of the SOFA tool, including:

- Where assessment of one or more components of SOFA or other tool is not possible due to a disability, health care providers are required to provide the patient a reasonable modification of the tool's scoring methodology. Patients should not be scored and should receive no SOFA points attributable to the component(s) that could not be assessed.[2]
- No points should be added to a patient's SOFA score based on baseline conditions not associated with acute illness where there is no objective medical evidence from which to conclude that such baseline conditions will impact short-term survival probability.

C. Withdrawal of Critical Care

[2] To the extent that proper SOFA scoring requires that patients who cannot be assessed under one or more components of SOFA due to a disability not be scored as to such component(s), the Guidelines must provide explicit instruction in that regard to avoid discrimination.

As stated in the prior section, federal disability civil rights laws 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 April 10 Guidelines fail to incorporate this principle and, indeed, potentially permit its violation by allowing critical care to be withdrawn from patients with disabilities before they have had an equal opportunity to benefit from treatment. April 10 Guidelines at 34. 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 April 10 Guidelines also allow doctors to use their "overall clinical judgment" to justify withdrawal of care. April 10 Guidelines at 34. This permits implicit bias and quality-of-life considerations to taint decision-making, leading to discrimination against people with disabilities.

D. Failure to Assure Effective Communication

The ADA and RA require that states and health care providers assure the provision of effective communication, including use of auxiliary aids and services, to individuals with disabilities, including those who are deaf, hard of hearing, blind, and visually impaired. *See* 28 C.F.R. §§ 35.160, 36.303(c), 41.51(e), 45 C.F.R. § 84.52(d). OCR reiterated the importance of complying with these provisions even with the context of the current pandemic. OCR Bulletin at 2.

The mandate to assure effective communication is particularly vital where, as here, it is literally a matter of life and death. A person who is deaf and cannot provide participate in the triage evaluation process without a sign language interpreter may be placed in a lower priority category. A person with a cognitive disability who relies on a "communicator" to help convey his needs and to understand information provided and questions asked may not be able to participate effectively in the triage process and treatment if his communicator is barred from the hospital.

The Guidelines do not include any provisions that require health care providers to comply with their federal obligations to assure effective communication. Without such guidance, it is possible that individuals with disabilities will be subject to discrimination in the triage process and treatment.

E. OCR Must Protect Vulnerable Pennsylvanians with Disabilities

DRP requests that OCR immediately investigate and issue a finding that the April 10 Guidelines unlawfully discriminate against individuals with disabilities. We request that you require DOH to modify its Guidelines as follows:

- Incorporate important non-discrimination principles contained in OCR's Bulletin, 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;
  - requirements that health care providers make reasonable modifications in its policies, practices, and procedures when necessary not to discriminate against people with disabilities;
  - 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.

- Eliminate the second step of the evaluation tools for adult and pediatric patients that adds points based on "prognosis for continued survival" and saving "life-years";
- Require DOH to modify step one of the evaluation tool for adult and pediatric patients to assure that reasonable modifications are made so that the use of SOFA, PELOD, or similar scoring tools do not discriminate against people with disabilities.
- Require DOH to modify the withdrawal of care guidelines for adult and pediatric patients to assure that reasonable modifications are made for individuals whose underlying disabilities require longer treatment to have an equal opportunity to benefit from treatment.
- Require DOH to modify the withdrawal of care guidelines for pediatric patients to prohibit health care providers from reallocating ventilators that pediatric patients use in daily life and bring with them to the hospital.
- Require DOH to incorporate meaningful review and oversight protections that act as a check to ensure that decisions are not being made on discriminatory bases.

We greatly appreciate your prompt consideration of this urgent matter. Please contact Kelly Darr, 215-238-8070 ext. 221 or kdarr@disabilityrightspa.org with any questions or responses to this Complaint.

Respectfully,

Kelly Darr
Legal Director

cc: Kevin Hoffman, Esq. (by email kjhoffman@pa.gov)