Disability Rights North Carolina

April 3, 2020

delivered by email to: mandy.cohen@dhhs.nc.gov

Secretary Mandy Cohen
NC Department of Health and Human Services
101 Blair Drive
Raleigh, NC 27603

Re: Scarce Inpatient Critical Care Resources in a Pandemic

Dear Secretary Cohen:

I write regarding the urgent matter of guidance to hospitals in allocating scarce resources during the COVID-19 pandemic, and specifically the protocol recommended by the Scarce Resource Allocation Steering Committee.

The Steering Committee is proposing a somewhat modified version of what has been dubbed the Pittsburgh Protocol. We agree with the proposed protocol's strong emphasis on individualized assessments based on clear medical criteria related to likelihood of survival, including the presence of conditions that will lead to death shortly after hospital discharge. However, in one critical area, the protocol fails to follow its own premise and violates disability rights law: reliance on a broad notion of "Major Comorbidities" invites the use of speculative and discriminatory consideration of disabilities unrelated to COVID-19.

Policies that disparately impact the ability of people with disabilities to access health care violate the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, Section 1557 of the Affordable Care Act, as well as Chapter 168A of the North Carolina General Statutes. *See* 42 U.S.C. § 12182 (defining discrimination to include "the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities"); 29 U.S.C. § 794(a) (prohibiting discrimination in access to federally funded programs); N.C. Gen. Stat. §

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168A-7 (prohibiting discrimination by public entities, including in the provision of health care); and *Crowder* v. *Kitagawa*, 81 F.3d 1480, 1483 (9th Cir. 1996) ("It is thus clear that Congress intended the ADA to cover at least some so-called disparate impact cases of discrimination, for the barriers to full participation listed above are almost all facially neutral but may work to effectuate discrimination against disabled persons.")

Reliance on "Major Comorbidities" in the proposed protocol will tend to "screen out" people with disabilities illegally by assigning them scores that are based, in part, on non-COVID-19 medical conditions. *See* 42 U.S.C. § 12182 (prohibiting use of discriminatory screening criteria); *see also*, *Alexander v. Choate*, 469 U.S. 287, 301, 105 S. Ct. 712, 720 (1985) ("The benefit itself, of course, cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are entitled".). The fact that the "Major Comorbidities" in the current protocol are listed as examples only further exacerbates this issue because it allows for medical professionals to greatly expand the number and type of disabilities that may lead to denial of care. Given the propensity for society to devalue the perceived quality of life and assumed longevity of people with certain conditions – and the extreme pressure under which these decisions will be made – this undefined factor is very likely to lead to discriminatory decision-making.

The use of "Major Comorbidities" also violates the principles contained in the protocol itself, as well as in the ADA and related statutes, and the recent US HHS OCR guidance that assessments must be individualized. It is insufficiently specific, veering sharply from the overall approach's reliance on quantifiable data points, and does not provide meaningful guidance for triage teams to assess comorbidities. It seems unlikely that, for example, a triage team could expect to have access to the necessary specialists to assess ten-year survival prospects for patients with developmental disabilities, traumatic brain injuries, metabolic diseases, and other complex comorbidities with the frequency this process would require. This is especially true outside of large research hospitals. It doubly penalizes people who are already likely to have higher SOFA scores. Moreover, as the span of time covered by survival predictions extends beyond the one-year threshold included in the protocol, assessments of how long particular patients might live become increasingly speculative. The longer the term of a survival prediction, the more it relies on epidemiological probability rather than an individual assessment of disease process. All of these factors tend to disadvantage people with disabilities in violation of federal and state law.

We appreciate the tremendous effort that has gone into developing guidance for medical professionals to ease, as much as possible, the moral burden of the decisions ahead. We implore you to ensure that those decisions are not tainted by discrimination. To that end, we ask that you remove the "Major Comorbidities" criteria before promulgating or publishing guidance for medical professionals to follow in allocating scarce resources during the pandemic.

As always, we are available to consult further on matters related to the lives and rights of people with disabilities in North Carolina.

Regards,

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CEO

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