Disability Rights North Carolina

December 1, 2020

Secretary Mandy Cohen
North Carolina Department of Health and Human Services
2501 Mail Service Center
Raleigh, NC 27699-2501

SENT VIA EMAIL: Mandy.Cohen@dhhs.nc.gov

RE: **North Carolina Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic**

Dear Secretary Cohen,

Again we write with regard to the North Carolina Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic ("Protocol"). As you are well aware, the pandemic is worsening nationally. In recent press conferences, you have noted that North Carolina's data of late are troubling. While we appreciate your efforts to expand capacity, Disability Rights North Carolina (DRNC) and the wider disability community are very concerned about the possibility of COVID-19 continuing to spread prolifically in the weeks to come. We continue to have grave concerns about the contents of the Protocol and the State's failure to adopt a clear set of standards for allocating critical care resources. Still today, the Protocol contains provisions very similar to those found to have violated federal disability rights statutes in two recent decisions by the U.S. Department of Health and Human Services' Office for Civil Rights. We are confident in our ability to address the Protocol through litigation if the State or any healthcare provider attempted to implement it, yet strongly prefer to resolve this matter amicably through the State's voluntary removal of the discriminatory provisions and adoption of a non-discriminatory version of the Protocol.

Our concerns about the contents of the Protocol are centered on long-term survivability and the SOFA. Long-term survivability is difficult to predict, and disadvantages people with

disabilities – often on the basis of assumptions and stereotypes about how long such persons are likely to live. The subjectivity and educated guesswork involved in making long-term survival predictions quickly, under extremely stressful working conditions, create a perfect opportunity for unconscious bias to pollute the allocation process and subvert the fair, transparent, individualized decision-making the Protocol was meant to promote. While we understand the rationale for considering short-term survivability under the extreme circumstances the Protocol is intended to address, the glaring, unlawful opportunities for bias to influence long-term survivability determinations is unacceptable.

We are also concerned about the Protocol's reliance on the SOFA without allowing for modifications as applied to people with disabilities. While the SOFA is a reasonable metric to use in people of normative physical and mental functioning, it will often count stable, chronic conditions that have nothing to do with the ability to benefit from critical care or survive COVID-19 against people with disabilities. For example, people with speech or motor impairments may be disadvantaged on the Glasgow Coma Scale, which we understand is incorporated into SOFA scoring. We do not suggest that the SOFA should be dispensed with if it is the best tool for healthcare providers to use to make difficult decisions under extreme circumstances. Rather, we request that the State comply with federal disability rights statutes by adopting a version of the Protocol that requires modification of the SOFA to account for patients' disabilities.

Both of DRNC's main concerns about the contents of the Protocol have arisen in other states. Tennessee and Pennsylvania adopted protocols for allocating scarce critical care resources similar to North Carolina's. In both cases, DRNC's counterparts filed OCR complaints. In both cases, the analogous provisions were found to violate federal disability rights statutes. In both instances, resolution of those complaints excised long-term survivability from consideration and required modifications to the SOFA where warranted due to disability. More information is available here.

The current text of North Carolina's Protocol is unlawful, and we will not stand by and allow it to be implemented. We also have grave concerns that the State's failure to adopt a non-discriminatory protocol could lead to subjective, chaotic decision-making and differing allocations across neighboring hospitals. In the absence of a protocol, people with disabilities, people of color, LGBTQIA individuals, and other marginalized people are at risk of being victimized by decision-making under pressure, without appropriate guidance.

The State's voluntary adoption of a non-discriminatory protocol would not just prevent chaotic decision-making that reinforces existing inequities, and litigation against any entity that attempts to implement the current version of the Protocol. It would also be a resounding

statement that North Carolina places equal value on the lives of its residents with disabilities, including the disproportionate number of people with disabilities who are also members of other minority groups. The State's voluntary adoption of a non-discriminatory Protocol would help facilitate trust in North Carolina's government and healthcare system among people with disabilities and their loved ones. I hope we can work together to achieve this outcome. Please contact me at (919) 856-2195 or virginia.knowltonmarcus@disabilityrightsnc.org to discuss this matter further.

Sincerely,

Virginia Knowlton Marcus
CEO

CC: Lisa Corbett
Kody Kinsley
Ben Money