



May 5, 2020

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

Re: Complaint of Disability Rights North Carolina concerning the North Carolina Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic

Dear Mr. Severino:

Our complaint concerns unlawful discrimination by the State of North Carolina, the North Carolina Institute of Medicine (NCIOM), the North Carolina Medical Society (NCMS), and the North Carolina Healthcare Association (NCHA) in their plans for allocating life-saving medical resources. We do not dispute the necessity of preparing for overwhelmed hospitals in light of the COVID-19 pandemic, but some provisions of the current iteration of the North Carolina Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic (Protocol) violate Title II of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act.¹ These legal violations threaten the lives of North Carolinians with disabilities. If implemented in response to COVID-19 or any future pandemic, the Protocol will wrongfully disadvantage patients with disabilities in need of critical care and leave North Carolina's disability community to shoulder an avoidably disproportionate share of the pandemic's death toll. These impacts will be particularly severe with regard to those disproportionately affected based on race or poverty, and those being subject to explicitly discriminatory treatment based on age. Due to the lethal and irreversible nature of the harm which will take place if the Protocol takes effect, it is crucial that the Office for Civil Rights (OCR) take

¹ The ADA, Section 504, and Section 1557 cover the state of North Carolina, NCMI, NCMS, NCHA, all North Carolina hospitals, health care providers, and health plans and insurers. See 42 USCS § 12182; see also 42 USCS § 12132; 29 USCS § 794; 42 USCS § 18116. These statutes prohibit discrimination on the basis of disability in the provision of healthcare. See 45 C.F.R. §§ 92.101(a), 92.101(b)(2)(i); see also Analysis Under the Americans with Disabilities Act (ADA) of the Oregon Reform Demonstration (Attachment to Letter from Louis W. Sullivan to Governor Barbara Roberts (Aug. 3, 1992)), reprinted in 9 Issues in Law & Medicine 397 (1994). This legal analysis is discussed in more detail in the attached complaint. See *Complaint of Disability Rights Washington, Self Advocates in Leadership, The Arc of the United States, and Ivanova Smith Against the Washington State Department of Health (WA DOH), the Northwest Healthcare Response Network (NHRN) and the University of Washington Medical Center (UWMC)* Mar. 23, 2020, https://www.centerforpublicrep.org/wp-content/uploads/2020/03/OCR-Complaint_3-23-20-final.pdf.

prompt action to address the discriminatory aspects of the Protocol and protect persons with disabilities.

Background Information

Disability Rights North Carolina (DRNC) is the designated Protection and Advocacy System for North Carolina residents with disabilities. The Protection and Advocacy Systems were mandated by the federal government in each state, district, commonwealth, territory, and the Native American nations in the Four Corners region to provide independent advocacy for people with disabilities who are subjected to abuse, neglect, and serious rights violations.² DRNC has served as North Carolina's Protection and Advocacy system for over ten years. Operating as an independent, nonprofit, nonpartisan legal organization, we protect and advocate for the rights of North Carolina residents with disabilities through litigation, policy advocacy, and education. Nothing could be more relevant to our mandate than a policy that threatens the lives of North Carolinians with disabilities.

When the danger of COVID-19 became apparent, the North Carolina Department of Health and Human Services (NCDHHS) authorized and deputized three organizations representing North Carolina's healthcare providers, NCIOM, NCMS, and NCHA, to create a scheme for allocating scarce medical resources. Although NCIOM, NCMS, and NCHA enjoy varying degrees of independence from the State, they acted as the State's agents in this matter, drafting the Protocol because NCDHHS had called upon them to do so. As instructed, they convened an advisory group of stakeholders. DRNC participated in discussions with the advisory group convened to create the Protocol.

We made every effort to voice the disability community's concerns and to ensure compliance with federal law. We became concerned about the contents of the Protocol and contacted NCDHHS to request compliance with Title II of the ADA and Section 504 of the Rehabilitation Act and the inclusion of a nondiscrimination provision on March 27, 2020. After a round of revisions failed to address all discriminatory provisions of the Protocol, we contacted NCDHHS again on April 3, 2020 to express our concern that the use of major comorbidities and long-range survival predictions in allocating scarce resources violates federal law. Three weeks later, without further discussion or consultation, NCIOM, NCMS, and NCHA published the Protocol on Saturday, April 25 with the discriminatory provisions still in place. The final version of the Protocol violates federal law and will disadvantage people with disabilities seeking lifesaving care under dire circumstances.

The Protocol will shape the allocation of critical care resources when pandemics strain healthcare system capacity with or without formal ratification by the State. The State initiated its creation. The organizations responsible for the Protocol are frequently involved in crafting healthcare policy and the exercise of state authority. NCIOM was chartered by the State primarily for the purpose of supporting the State in crafting healthcare policy.³ NCMS is similarly entangled with public functions, including

² Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15041 et seq.; the Protection and Advocacy for Individuals with Mental Illnesses Act, as amended, 42 U.S.C. § 10801, et seq.; the Protection and Advocacy for Individual Rights Act, 29 U.S.C. § 794e.

³ NCIOM was chartered by the State of North Carolina. See N.C.G.S. § 90-470(a) ("The persons appointed under the provisions of this section are declared to be a body politic and corporate under the name and style of the North Carolina Institute of Medicine..."). Its mandate includes "[r]espond[ing] to requests from outside sources for analysis and advice when this will aid in forming a basis for health policy decisions." N.C.G.S. § 90-470(b)(4). The State regulates the sources from which it can receive funding. See N.C.G.S. § 90-470(e) ("The North Carolina Institute of Medicine may receive and administer funds from private sources, foundations, State and county governments, federal agencies, and professional organizations."). NCIOM exists "under the patronage and control of the State." N.C.G.S. § 90-470(g).

health policy and physician rehabilitation and support, and has been one of the most authoritative voices in medicine for generations of North Carolina doctors.⁴ NCHA represents North Carolina's healthcare systems. See North Carolina Healthcare Association, *About NCHA* (Apr. 27, 2020), <https://www.ncha.org/about-ncha/>. Its role as the voice of North Carolina's healthcare systems also gives it considerable influence in healthcare policy. Due to the nature and influence of its authors, there is no doubt that the Protocol will be implemented and will control the allocation of critical care resources if the conditions triggering its use arise. Because the discrimination embedded in the Protocol will be made manifest in the event that critical care resources become scarce in North Carolina, it is crucial that OCR act quickly to resolve this matter.

The North Carolina Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic

While the Protocol was written in response to concerns about the effect of COVID-19 on North Carolina's healthcare systems, it is not limited to the current crisis. It also covers future pandemics. The Protocol applies to all adults in need of critical care resources "when 1) the Governor has declared a state of emergency (NCGS §166A) due to a pandemic (such as the current COVID-19 pandemic), and 2) critical care resources are, or shortly will be, overwhelmed." See *North Carolina Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic*, 1 (April 25, 2020). When the Protocol is put into effect, patients will be assigned numerical scores. These scores correspond to priority decisions about the allocation of critical care resources. Lower scores correlate to higher priority for lifesaving care. See *Id.* at 5-7. Patients with the lowest scores are first in line to receive critical care resources, such as access to hospitals' ventilators and dialysis machines. If health care resources are scarce, those relegated to the lower priority groups – including individuals with disabilities and other underlying comorbid conditions – will be denied life-saving care, and likely die as a result.

The North Carolina Protocol Violates Federal Law

A. Legal Standards

Title II of the ADA prohibits public entities, including state and local governments, from excluding people with disabilities from their programs, services, or activities, denying them the benefits of those services, programs, or activities, or otherwise subjecting them to discrimination. 42 U.S.C. §§ 12131-12134. Implementing regulations promulgated by the United States Department of Justice (DOJ) define unlawful discrimination under Title II to include, inter alia: using eligibility criteria that screen out, or tend to screen out, individuals with disabilities, failing to make reasonable modifications to policies and practices necessary to avoid discrimination, and perpetuating or aiding discrimination by others.

⁴ NCMS has existed since 1849. See North Carolina Medical Society, *About NCMS* (Apr. 27, 2020), <https://www.ncmedsoc.org/about-ncms/>. The State officially sanctions its activities and, in some cases, regulates them. See N.C.G.S. § 90-1 ("The association of regularly graduated physicians, calling themselves the State Medical Society, is hereby declared to be a body politic and corporate... The name of the society is now the North Carolina Medical Society."); see also N.C.G.S. § 130A-213. It is authorized to fulfil numerous and important public functions. See *Id.* ("In implementing this Part, the Department shall consult with the Cancer Committee of [NCMS]... Any proposed rules or reports affecting the operation of the cancer control program shall be reviewed by the Committee for comment prior to adoption."); see also N.C.G.S. § 90-21.22(a) ("The North Carolina Medical Board... may enter into agreements with [NCMS]... for the purposes of identifying, reviewing, and evaluating the ability of licensees of the Board who have been referred to the Program to function in their professional capacity and to coordinate regimens for treatment and rehabilitation."); N.C.G.S. § 143-510(a) ("The North Carolina Emergency Medical Services Advisory Council shall consist of 25 members... Three of the members shall represent [NCMS] and include one licensed pediatrician, one surgeon, and one public health physician.").

28 C.F.R. §§ 35.130(b)(1)-(3), 35.130(b)(7)-(8). Moreover, DOJ has explicitly determined that Title II of the ADA applies to the emergency preparedness efforts of state and local governments, writing:

One of the primary responsibilities of state and local governments is to protect residents and visitors from harm, including assistance in preparing for, responding to, and recovering from emergencies and disasters. State and local governments must comply with Title II of the ADA in the emergency- and disaster-related programs, services, and activities they provide.⁵

Section 504 of the Rehabilitation Act similarly bans disability discrimination by recipients of federal financial assistance, including some state agencies, hospitals, and other healthcare providers. *See* 29 U.S.C. § 794(a). The breadth of Section 504's prohibition on disability discrimination is co-extensive with that of the ADA. *See, e.g., Frame v. City of Arlington*, 657 F.3d. 215, 223 (5th Cir. 2011) ("The, ADA and the Rehabilitation Act are generally interpreted in *pari materia*.").

The ADA and Rehabilitation Act bar the use of eligibility criteria that screen out or tend to screen out individuals with disabilities from access to services. *See, e.g.,* 42 U.S.C. § 12182(b)(2)(A)(i); 28 C.F.R. § 36.301 (ADA public accommodations); 28 C.F.R. § 35.130(b)(8) (ADA public entities).

Section 1557 of the ACA provides that no health program or activity that receives federal funds may exclude from participation, deny the benefits of their programs, services or activities, or otherwise discriminate against a person protected under Section 504 of the Rehabilitation Act, 42 U.S.C. § 18116; 45 C.F.R. §§ 92.101(a), 92.101(b)(2)(i). This includes an obligation to make reasonable modifications in policies, practices, and procedures necessary to avoid discrimination. *See* 45 C.F.R. § 92.205.

B. The Protocol's consideration of comorbid conditions at both stages of the triage process discriminates against patients with disabilities, aging adults and others with chronic, underlying conditions.

No patient should be disqualified from life-saving treatment solely because of comorbid conditions. However, the Protocol's emphasis on "saving the most life-years" is likely to result in exactly that for people with disabilities. Because the Protocol states that "[p]atients who do not have serious comorbid illness are given priority[,] " people with disabilities, which may be deemed co-morbid conditions, will face disproportionate denials of care under the Protocol. *North Carolina Protocol* at 6; 42 USCS § 12102; 29 USCS § 705(9); 42 USCS § 18116. They will be penalized at both stages of the triage process in two distinct ways: 1) in calculating the Sequential Organ Failure Assessment (SOFA) score; and 2) by adding additional "points" for life limiting and severe co-morbid conditions.

1. The SOFA will raise the priority scores of patients with disabilities.

The SOFA is intended to assess short term impairments arising out of an acute care episode and their impact on survivability to discharge.⁶ Instruments like the SOFA may inappropriately penalize individuals with stable, chronic disabilities even when based on individualized medical evidence. For example, the Glasgow Coma Scale, a tool used for measuring acute brain injury severity in the SOFA, adds points to a patient's score when the patient cannot articulate intelligible words even if this

⁵ *See* DOJ, Emergency Management Under Title II of the Americans with Disabilities Act at 1 (July 26, 2007), available at <https://www.ada.gov/pcatoolkit/chap7emergencymgmt.htm>.

⁶ *See* ClinCalc.com, SOFA Calculator: Sequential Organ Failure Assessment (SOFA) Severity of Illness Score for Hospital Mortality, available at <https://clincalc.com/IcuMortality/SOFA.aspx>.

condition is due to a pre-existing speech disability. The Glasgow Coma scale also disadvantages patients with pre-existing motor impairments because it requires moving in response to verbal commands.

Triage teams must avoid penalizing individuals with chronic, stable underlying conditions when calculating SOFA scores. Baseline levels of impairment prior to the acute care episode should not increase SOFA scores unless objective medical evidence, interpreted by a medical professional with expertise necessary to exercise professional judgment under usual standards of care, demonstrates that those conditions directly impact an individual's short-term survivability with treatment. The Protocol makes no provision for reasonable accommodations in SOFA scoring to ensure that underlying disabilities, or other co-morbid conditions not associated with short-term survivability, are not reflected in the SOFA scoring process. Such accommodations may include increasing the priority tier thresholds for critical care, or specifically excluding underlying impairments where no compelling evidence exists that those conditions will impact short-term survivability. Because some states have revised their scarce resource allocation schemes to avoid penalizing patients for underlying disabilities or comorbid conditions that do not impact short-term survivability, there are nondiscriminatory models North Carolina could follow.⁷

Your office has made clear that States must: 1) remove criteria that automatically deprioritized persons on the basis of particular disabilities; 2) require individualized assessments based on the best available, relevant, and objective medical evidence to support triaging decisions; and 3) ensure that no one is denied care based on stereotypes, assessments of quality of life, or judgments about a person's "worth" based on the presence or absence of disabilities.⁸

Because North Carolina allows the SOFA to lower an individual's priority for lifesaving care based solely on the presence of chronic, but stable, underlying conditions like diabetes, chronic kidney disease, developmental disability, brain injury, or speech and motor impairments, it violates federal anti-discrimination laws and directives from OCR.

2. The provision requiring additional points for comorbid conditions is contrary to OCRs directive the providers rely on individualized, objective medical evidence.

The ADA and Rehabilitation Act prohibit eligibility criteria that tend to screen out people with disabilities from access to services. However, the provision of the Protocol requiring the addition of points to the priority score of patients with comorbid conditions will have this effect because people with disabilities, by definition, have conditions that will automatically add points to their scores. *See*

⁷ Massachusetts, Pennsylvania and Delaware have all revised their Crisis Standards' calculation of SOFA scores to avoid penalizing patients for underlying disabilities or co-morbid conditions that do not impact short term survivability. *See, e.g.*, "Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic," April 20th 2020, 17, <https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download>; "Pennsylvania's Interim Crisis Plan," April 10, 2020, Version 2, 30, <https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID-19%20Interim%20Crisis%20Standards%20of%20Care.pdf>; Delaware Health and Social Services, Crisis Standards of Care Concept of Operations, April 28, 2020, (7.6.2Iii), <https://www.centerforpublicrep.org/wp-content/uploads/2020/05/DE-CSC-ConOps-FInal-4-29-20.pdf>

⁸ U.S. Dep't. of Health and Human Servs., HHS.gov, *OCR Resolves Civil Rights Complaint Against Pennsylvania After it Revises its Pandemic Health Care Triage Policies to Protect Against Disability Discrimination* (May 1, 2019), <https://www.hhs.gov/about/news/2020/04/16/ocr-resolves-civil-rights-complaint-against-pennsylvania-after-it-revises-its-pandemic-health-care.html>

North Carolina Protocol at 6. This is true even if their underlying conditions are stable and have no bearing on their ability to benefit from intensive care services, including ventilation.

To the extent that the additional points provision is an effort to save life-years by allocating scarce critical care resources to patients perceived as having the longest life expectancies, it is unreliable, subject to bias, and discriminatory because such prognoses are based on statistical norms across conditions and populations and not individualized medical evidence.⁹ Applying such statistics to decisions about individuals contravenes a central principle of the ADA and Rehabilitation Act: that covered entities' decisions about accommodating people with disabilities must be based on individualized determinations using objective evidence.¹⁰ Making life-or-death determinations about individuals based on population statistics, rather than individual characteristics and circumstances, flouts both federal disability rights statutes and the bulletin issued by OCR on March 28, 2020.¹¹

Pandemics will generally be novel, involving a new disease or a new strain of an existing disease. It will not always be immediately clear which populations are most endangered by an unfamiliar illness and whether a given comorbidity is likely to decrease a given patient's likelihood of survival.¹² This is particularly true in the early months of dealing with a new infectious disease, when much remains to be learned about how the illness affects the body. Whether any, or a given, comorbid condition equates to worse prospects of recovering from an acute infection without further consideration of individual circumstances is not often unknowable under the circumstances the Protocol is designed to address.

The assumption that comorbid conditions, on the whole, are a proxy for prospects of surviving a given disease without supporting evidence or consideration of individual characteristics and circumstances are precisely the kind of decision-making the ADA and Rehabilitation Act were intended to prevent. State triage protocols cannot treat disabled patients as unqualified for lifesaving care on the basis of assumptions, when there is no evidence that their disabilities affect their chances of benefiting from the care being sought. "Long standing and authoritative interpretations of the law bar the use of such circular techniques to insulate disability discrimination from legal challenge."¹³

⁹ See D.A. Rizzi, *Medical Prognosis – Some Fundamentals*, 15 *Theor. Med.* 4, 365 (1993).

¹⁰ See *School Bd. of Nassau County v. Arline*, 480 U.S. 273, 284-85, 287 (1987); see also *PGA Tour, Inc. v. Martin*, 532 U.S. 661, 688 (2017) ("To comply with this command, an individualized inquiry must be made to determine whether a specific modification for a particular person's disability would be reasonable under the circumstances as well as necessary for that person, and yet at the same time not work a fundamental alteration."); *Wright v. N.Y. State Dep't of Corr. & Cmty. Supervision*, 831 F.3d 64, 77, (2d Cir. 2016) ("...we conclude that the individualized inquiry requirement is applicable to failure to accommodate actions under Title II of the ADA as well."); *Marble v. Tennessee*, 767 Fed. Appx. 647, 652 (6th Cir. 2019) ("Although *PGA Tour* is a Title III case, the Supreme Court's reasoning makes clear that the individualized inquiry requirement also applies to requests for accommodation under Title II.").

¹¹ See <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.

¹² See Quiang Liu, Yuan-hong Zhou, and Zhan-qui Yang, *The Cytokine Storm of Severe Influenza and the Development of Immunomodulatory Therapy*, 16 *Cell Mol. Immunol.* 1, 3 (2016) (describing the 1918 influenza epidemic's disproportionate death toll among people who were young and healthy); see also D.M.G. Haplin, R. Fanner, O. Sibila, J.R. Baida, A. Agusti, *Do chronic respiratory diseases or their treatment affect the risk of SARS-CoV-2 infection?*, 20 *Lancet Resp. Med.* 30, 167 (2020) (discussing uncertainty about whether chronic lung disease increases the risk of contracting COVID-19 and similar conditions and the risk of serious complications); David Pierson, *If I become infected with the coronavirus, what are my odds of survival?*, L.A. Times, 2020, at Science, <https://www.latimes.com/science/story/2020-03-19/coronavirus-odds-of-survival> (last visited Apr. 30, 2020) ("The full burden of disease is not understood until there is time to breathe and analyze the data," said Gene Olinger, an immunologist with MRIGlobal, a scientific institute based in Kansas City, Mo.).

¹³ Samuel R. Bagenstos, *May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing*, University of Michigan Law School, p.2, March 24, 2020, available at https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3559926.

C. The Protocol's goal of saving "life years" discriminates against people with disabilities.

Although the Protocol does not categorically exclude patients based on diagnosis, it relies heavily on maximization of efficiency in allocating lifesaving resources, with the stated goal of saving life years. These principles – efficiency and saving life years – discriminate against people with disabilities and members of other protected classes, who tend to experience shorter life expectancies.

Importantly, the American College of Physicians has rejected the use of long-term prognosis or “number of life years,” instead recommending that hospitals make resource allocation decisions

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.¹⁴

Additionally, the Protocol uses life stage considerations to determine how lifesaving resources will be allocated between patients with the same triage score. *See North Carolina Protocol* at 7. This “tie-breaker” provision violates the Affordable Care Act’s anti-discrimination provisions, as well as the Age Discrimination Act of 1975, which establishes that “no person ... shall, on the basis of age, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under, any program or activity receiving Federal financial assistance.” 42 U.S.C. § 6102.

The Protocol uses this discriminatory criterion for allocating critical care resources despite the existence of nondiscriminatory models. For example, New York State has charted a different course. Its ventilator guidelines eliminate any consideration of comorbidity or long-term prognosis.¹⁵ Instead, they assess “the short-term likelihood of survival of the acute medical episode,” and not “whether a patient may survive a given illness or disease in the long-term (e.g., years after the pandemic). By adopting this approach, every patient is held to a consistent standard. Triage decision-makers should not be influenced by subjective determinations of long-term survival, which may include biased personal values or quality of life opinions.”¹⁶

D. Assessments of long-term prognosis based on “significant life limiting co-morbidities” are prone to discriminatory assumptions, unconscious bias, and clinical error, and exacerbate underlying inequities in the health care system.

The Protocol provides no objective, reliable, or consistent means of informing decisions on intermediate or long-term prognosis. Populations whose health and longevity are negatively impacted by inequities in access to care will be doubly harmed because the Protocol’s criteria will lead to discriminatory assumptions and perpetuate unconscious bias in the provision of lifesaving care.¹⁷

¹⁴ Available at <https://www.acponline.org/acp-newsroom/internists-say-prioritization-allocation-of-resources-must-not-result-in-discrimination>.

¹⁵ New York State Department of Health, “Ventilator Allocation Guidelines,” by the New York Taskforce on Life and the Law, November 2015, 34, available at

https://www.health.ny.gov/regulations/task_force/reports_publications/docs/ventilator_guidelines.pdf.

¹⁶ Elios Rivera-Segarra, et. al., “That’s All Fake”: Health Professionals, Stigma and Physical Healthcare of People Living with Serious Mental Illness, 14 PloS One, 12, (2019) available at <https://doi.org/10.1371/journal.pone.0226401>.

¹⁷ See Joseph Stramondo, COVID-19 Triage and Disability: What Not to Do, Bioethics.net, March 30, 2020, available at <http://www.bioethics.net/2020/03/covid-19-triage-and-disability-what-not-to-do/>; see also Cholë FitzGerald & Sania Hurst, Implicit Bias in Healthcare Professionals: A Systemic Review, 18 BMC Med. Ethics (2017) available at

Further, the Protocol fails to include safeguards against such influences in the decision-making process, including required triage training on implicit bias.¹⁸ Similarly, attempts to predict and score patients based on long-term prognosis are subjective and uncertain. The use of such predictions will lead to inconsistent decision-making, higher rates of clinical error, and discriminatory allocation of care.

By incorporating comorbidities that do not reduce a patient's short-term survival prospects into the triage assessment, the Protocol creates a substantial risk that quality of life and other subjective value judgments will also be improperly incorporated into the process, reducing the likelihood persons with disabilities and chronic health conditions will receive medically indicated care.¹⁹ Because the criteria in the Protocol effectively constitute a proxy for quality of life, they directly contravene OCR's Bulletin and federal civil rights laws. Instead of the discriminatory process in the Standards, triage decisions should be governed by individualized assessments of the patient's potential for survivability to discharge given treatment for the acute, pandemic disease.

Encouraging doctors to predict which patients are likely to live longest opens the door to discrimination on the basis of disability.²⁰ Stereotypes, unwarranted assumptions, and unconscious biases about people with disabilities are common in medical settings, particularly in the context of severe or life-threatening illness.²¹ It is highly likely that individuals with disabilities will be perceived as having "life-limiting" or "severe" co-morbidities, based on discriminatory assumptions about their conditions, or misperceptions about the value and utility of their lives.²² Stressful situations and decision-making under time pressure tend to bring unconscious biases to the fore, and medical

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5333436/> (meta-analysis of 49 articles on the impact of implicit race and gender bias in the provision of medical care concludes that "healthcare professionals exhibit the same levels of implicit bias as the wider population" and that bias is "likely to influence diagnosis and treatment decisions and levels of care in some circumstances"); see also Clarissa Kripke, Patients with Disabilities: Avoiding Bias When Discussing Goals of Care, 93 Am. Fam. Physician 192 (2017) available at <https://www.aafp.org/afp/2017/0801/p192.html> ("[f]alse assumptions about patients' quality of life can affect prognosis" and even "result in premature withdrawal of life-preserving care.")

¹⁸ Pennsylvania's Standards include requirements for triage officer crisis training, including training on implicit bias.

"Pennsylvania's Interim Crisis Plan," April 10, 2020, Version 2, 27,

<https://www.health.pa.gov/topics/Documents/Diseases%20and%20Conditions/COVID-19%20Interim%20Crisis%20Standards%20of%20Care.pdf>

¹⁹ The Department of Health and Human Services rejected Oregon's plan to ration Medicaid services in the early 1990s that included criteria based upon quality of life and likelihood of treatment returning the patient to an asymptomatic state, concluding that such criteria violate the ADA based on stereotypical assumptions about people with disabilities' quality of life. See Timothy B. Flanagan, ADA Analyses of the Oregon Health Plan, 9 Issues in Law & Medicine 397 (1994) (reprinting federal analyses that Oregon's proposals to ration health care violated the ADA).

²⁰ See National Council on Disability, Medical Futility and Disability Bias, 9-10 (2019) ("It has been well documented that healthcare providers significantly undervalue life with a disability... As a result, healthcare providers remain largely unaware of the high quality of life and happiness that many people with disabilities experience. This lack of awareness has impacted medical futility decision making and, in some cases, robbed people with disabilities of their chance to recover.").

²¹ See Tiffani J. Johnson, Robert W. Hickey, Galen E. Switzer, Elizabeth Miller, Daniel G. Winger, Margaret Nguyen, Leslie R. M. Hausmann, and Richard A. Saladino, *The Impact of Cognitive Stressors in the Emergency Department on Physician Implicit Racial Bias*, 23 Acad Emerg Med. 3, 297 (2016).

²² See generally *Id.* at 31 ("Several studies have demonstrated that health care providers' opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people. For example, one study found that only 17 percent of providers anticipated an average or better quality of life after a spinal cord injury (SCI) compared with 86 percent of the actual SCI comparison group. The same study found that only 18 percent of emergency care providers imagined that they would be glad to be alive after experiencing a spinal cord injury, in contrast to the 92 percent of actual SCI survivors.") (footnotes omitted).

professionals are not exempt from such biases' effects on reasoning and judgement.²³ Indeed, implicit bias among medical professionals is well-documented.²⁴

For these reasons, permitting medical providers to make long-range guesses about which patients represent opportunities for "saving the most life-years" is likely to result in underestimates of patients with disabilities' prospective lifespans. *North Carolina Protocol* at 6. The Protocol will consequently result in people with disabilities being disproportionately denied access to critical care even in cases where a patient with a disability could likely make a full recovery from the acute condition at hand. Such conduct is wholly at odds with federal non-discrimination statutes as it de-prioritizes certain people based on disability diagnosis.²⁵

The ADA and Rehabilitation Act prohibit covered entities from making decisions based on myths, stereotypes, and unfounded assumptions about people with disabilities. *See School Bd. of Nassau County v. Arline*, 480 U.S. 273, 284-85, 287 (1987). OCR's recent Bulletin also made clear that it is unlawful to make treatment decisions based on "judgments about a person's relative 'worth' based on the presence or absence of disabilities."²⁶ The Protocol's use of comorbid conditions to allocate critical care resources, even where such conditions do not negatively affect an individual's short-term survivability, allocates lifesaving resources on these prohibited bases.

Moreover, people with disabilities have long experienced discrimination in their access to medical and preventative health care.²⁷ Over time, this discriminatory treatment leads to more co-morbid conditions and lower than average longevity. For instance, people with psychiatric disabilities are among those with lower life expectancies due to co-morbidities associated with years of antipsychotic medication and related side-effects, a history of segregation and substandard treatment, and marginalization in access to health care.²⁸

²³ *See Johnson et. al, Cognitive Stressors, supra.*

²⁴ The prevalence of unconscious bias in the provision of health care generally is well documented. *See Cholè FitzGerald & Sania Hurst, Implicit Bias in Healthcare Professionals: A Systemic Review*, 18 BMC Med. Ethics (2017) available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5333436/> (meta-analysis of 49 articles on the impact of implicit race and gender bias in the provision of medical care concludes that "healthcare professionals exhibit the same levels of implicit bias as the wider population" and that bias is "likely to influence diagnosis and treatment decisions and levels of care in some circumstances"); *see also* Clarissa Kripke, Patients with Disabilities: Avoiding Bias When Discussing Goals of Care, 93 Am. Fam. Physician 192 (2017) available at <https://www.aafp.org/afp/2017/0801/p192.html> ("[f]alse assumptions about patients' quality of life can affect prognosis" and even "result in premature withdrawal of life-preserving care.").

²⁵ *See Wagner v. Fair Acres Geriatric Center*, 49 F.3d 1002, 1015 (3d Cir. 1995) (holding that nursing home could violate Section 504 of the RA and Title II of the ADA by excluding a person with Alzheimer's disease who would require a higher level of care); *see also Lovell v. Chandler*, 303 F.3d 1039, 1053 (9th Cir. 2002) (holding that state's exclusion of people who were blind or disabled from a new managed care program violated Section 504 and Title II of the ADA), cert. denied, 537 U.S. 1105 (2003).

²⁶ *See*, n. 11, *supra*.

²⁷ *See, e.g.,* NAT'L COUNCIL ON DISABILITY, ORGAN TRANSPLANT DISCRIMINATION AGAINST PEOPLE WITH DISABILITIES (Sept. 25, 2019), available at https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf.

²⁸ World Health Organization, Information Sheet: Premature death among persons with severe mental disorders (reporting 10-25 year life expectancy reduction) available at https://www.who.int/mental_health/management/info_sheet.pdf; *see also* Thomas Insel, Post by Former NIMH Director Thomas Insel: No Health Without Mental Health, Nat'l Instit. of Mental Health (September 6, 2011)(Citing studies that "Americans with major mental illness die 14 to 32 years earlier than the general population.") available at <https://www.nimh.nih.gov/about/directors/thomas-insel/blog/2011/no-health-without-mental-health.shtml>; M. De Hert, et al., Physical Illness in Patients with Severe Mental Disorders, 10 World Psychiatry 52 (2011) (people with SMI receive inadequate treatment by health care providers; "... stigmatization, discrimination, erroneous beliefs and negative attitudes associated with SMI will have to be eliminated to achieve parity in

If there is any consideration of short-term survivability beyond discharge, clinicians should be instructed to make conservative judgments regarding prognosis, relying upon individualized assessment and the most expert clinical judgment available to them. Triage officers should not assign points based on the mere existence of underlying medical conditions, or when prognosis is uncertain.

E. The Protocol fails to require the provision of reasonable accommodations in, and reasonable modifications to, the triage process for people with disabilities.

The Protocol does not mention requirements under the ADA and Section 504 to make reasonable accommodations for people with disabilities. It does not remind healthcare facilities of their federal and state anti-discrimination obligations to make reasonable modifications to their policies and practices when necessary to allow persons with disabilities to enjoy the benefits and services they provide. For example, the explanation of how long patients should be allowed to remain on ventilators suggests that the period allotted to patients to show progress toward recovery “should be modified as appropriate if subsequent data emerge that suggest the trial duration should be longer or shorter” but makes no mention of the need to extend the trial duration due to disability in some cases. *See North Carolina Protocol* at 9. Similarly, the Protocol fails to specify that patients who enter the hospital with a personal ventilator should not have it removed and given to another patient.²⁹

Treatment allocation decisions may not be made based on the perception that a person’s disability will require the use of greater treatment resources, either in the short or long term. This should preclude the denial or withdrawal of a scarce medical resource, such as a ventilator, based on the assumption that the person will require its use for a longer period of time. Given that the clinical trajectory for any one patient is also influenced by their underlying conditions, including permanent disabilities, clinicians should consider these factors and allow for variations on recovery in the context of the underlying condition or disability.”³⁰ This will sometimes involve extension of the therapeutic trial.

Patients with disabilities may also require specific accommodations in communicating their needs and preferences regarding treatment, including access to interpreters and specialized assistive technology. It is critical that all reasonable steps be taken to ensure guardians, family members, and health care agents are afforded an equal opportunity to communicate with the disabled individual, their treating clinicians, and the triage assessment team. If necessary, this communication should be facilitated through specialized interpreters or telephonic or video technology that is effective for, and accessible to, the person and their supporters. The Protocol fails to provide for these accommodations in the

health care access and provision.”) and/or N. Liu, et al., *Excess Mortality in Persons with Severe Mental Disorders: A Multilevel Intervention Framework and Priorities for Clinical Practice, Policy and Research Agendas*, 16 *World Psychiatry* 30 (2017) Although persons with serious mental illness have two times as many health care contacts, they receive fewer physical check-ups and screenings, fewer prescriptions and less treatment for physical ailments than other patients.).

²⁹ Massachusetts and Delaware expressly prohibit reallocation of personal medical equipment when a patient presents at the hospital. *See Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic*, April 20, 2020, at 26, <https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download> (“Patient personal equipment: If a patient presents to a hospital and has personal medical equipment, such as a ventilator, that equipment will not be confiscated or used for any other patient.”); *see also Delaware Health and Social Services, Crisis Standards of Care Concept of Operations, April 28, 2020, (7.6.2liv)*, <http://> (“Individuals presenting for hospital level of care will not be subject to the automatic withdrawal or redeployment of personal lifesaving equipment, including ventilators, based on discriminatory assumptions about their intensity of need or likelihood of recovery.”).

³⁰ “Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,” April 20, 2020, 23,

<https://www.mass.gov/doc/statewide-advisory-committee-recommendations-for-standards-of-care/download>

triage process, further excluding some members of the disability community from receiving adequate care.

Finally, if a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or disability service provider knowledgeable about the management of their care to physically or emotionally assist them during their hospitalization, this accommodation should be allowed with proper precautions taken to contain the spread of infection.³¹

The Protocol's failure to provide for assistance from a caregiver as an accommodation in the triage process will place individuals with behavioral support needs and cognitive disabilities at high risk of adverse outcomes, deprive bedside clinicians of critical medical information, and effectively exclude people with disabilities from fully benefiting from the available healthcare resources. The American Academy of Developmental Medicine and Dentistry (AADMD) recommends that hospitals "provide reasonable accommodations in their visitor policies for persons who need support from known and acknowledged support persons (family, community agency personnel, or other designated caregivers)." Importantly, AADMD notes that without accommodations to "no visitor" policies, physicians may be deprived of critical health care information in the triage process, and patients can experience "deleterious and sub-optimal clinical outcomes because vital bio-psycho-social information is not available to medical staff."³²

OCR Must Protect All North Carolina Residents Without Discrimination

The Protocol is both discriminatory on its face and, if implemented, virtually certain to foster, facilitate, and result in further unlawful discrimination with deadly consequences. Whether the State formally adopts the Protocol or not, people with disabilities are aware that it will take effect if its triggering conditions arise. If the Protocol is implemented, it will shunt people with disabilities to the back of the line for critical care, consigning them to premature, preventable, and needless deaths. For this reason, North Carolina residents with disabilities, particularly those who are older adults, people of color, or incarcerated persons who can do little to protect themselves from infection, are experiencing intense fear and anxiety because of the Protocol. These individuals are aware that they are not only at heightened risk of contracting the COVID-19 virus but also more likely to be denied lifesaving care in the event that healthcare rationing under the attached Protocol takes effect. Because the Protocol's applicability is not limited to the current pandemic, the present climate of fear will return every time a pandemic disease threatens to overwhelm our critical care resources unless the discriminatory aspects of the Protocol are addressed.

Because the Protocol's implementation would cause the grave and irreversible harm of untimely deaths, we request that OCR immediately investigate and issue a finding that the Protocol unlawfully

³¹ See, e.g. New York Department of Health, Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation, https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf; New Jersey Department of Health, Support Person Permitted for a Patient with a Disability, April 25, 2020, [https://njcdd.org/wpcontent/uploads/VisitorPolicy.pdf#%5D.+?\)%5B'%22%5D\)&link_id=45079976764548&source_id=45079984840849&source_type=Contact](https://njcdd.org/wpcontent/uploads/VisitorPolicy.pdf#%5D.+?)%5B'%22%5D)&link_id=45079976764548&source_id=45079984840849&source_type=Contact)

³² AADMD "Hospitalized Patients & Designated Support Staff Policy Statement Committee on Public Policy and Advocacy," April 2020, <https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5e9e1cbefc832d0a6866fed4/1587420352080/Visitation-PolicyStatement.pdf>.

discriminates against these individuals in violation of federal law. Urgent action is needed given the ongoing threat of the COVID-19 pandemic, and the climate of fear it creates and devaluation of the lives of people with disabilities it demonstrates cause harm even now, while it is not yet in effect.

We further request that your Office advise North Carolina that it must either repudiate the Protocol and take action to prevent its use in North Carolina healthcare facilities or develop a revised, mandatory, nondiscriminatory protocol for crisis care. The revised Protocol must:

- 1) prohibit consideration of disability or age independent of its impact on short term survival from COVID-19;
- 2) include an explicit assurance that all individuals are qualified for, and eligible to receive, lifesaving care, regardless of diagnosis, functional impairment or activities of daily living needs;
- 3) ensure that all triage decisions must result from individualized assessments based on objective medical evidence;
- 4) eliminate “life-limiting co-morbidities” or “long term prognosis” as factors in triage scoring protocols;
- 5) require that the Standards include reasonable accommodations/modifications of the triage protocol for people with disabilities.

In addition, to address related discrimination based on race and/or age, any revised Protocol must:

- 6) prohibit any implementation of the Standards that would result in discriminatory treatment or impact on populations protected by Title VI of the Civil Rights Act of 1964, the Age Discrimination Act of 1975, and Section 504 of the Rehabilitation Act of 1973; and
- 7) eliminate age as a “tie-breaker,” when individuals otherwise have similar priority scores.

Thank you for your attention. We look forward to your response.

Sincerely,

Virginia Knowlton-Marcus
Lisa Grafstein
R. Larkin Taylor-Parker
Disability Rights North Carolina
3724 National Dr.
Suite 100
Raleigh, NC 27612
(919) 856-2195
virginia.knowltonmarcus@disabilityrightsn.org
lisa.grafstein@disabilityrightsn.org
larkin.taylor-parker@disabilityrightsn.org

Shira Wakschlag
The Arc of the United States
825 K St. NW
Suite 1200
Washington, D.C. 20006
(202) 534-3708
wakschlag@thearc.org

John Nash
The Arc of North Carolina
353 E Six Forks Rd.
Suite 300
Raleigh, NC 27609
(919) 782-4632
jnash@arcnc.org

Jennifer Mathis
Bazelon Center for Mental Health Law
1090 Vermont Avenue, NW
Suite 220 Washington, DC 20005
jenniferm@bazelon.org

Samantha Crane
Autistic Self Advocacy Network
P.O. Box 66122
Washington, DC 20035
(202) 509-0135
scrane@autisticadvocacy.org

Samuel Bagenstos
625 South State Street
Ann Arbor, Michigan 48109
(734) 647-7584
sbagen@gmail.com

Cathy Costanzo
Alison Barkoff
Center for Public Representation
22 Green Street
Northampton, MA 01060
(413) 586-6024
ccostanzo@cpr-ma.org
abarkoff@cpr-us.org