March 27, 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:

Thank you to you and your staff for the important and difficult work being done to respond to the COVID-19 crisis.

We are writing today regarding the urgent issue of scarce resource allocation. We have appreciated the ability to review and discuss with the Scarce Resource Allocation Advisory Group convened by the NC Institute of Medicine and Department staff the draft Protocol for Allocating Scarce Inpatient Critical Care Resources in a Pandemic ("Draft Protocol"). We support the Department and/or Governor's office issuing a state-wide mandatory policy for health care providers to provide clear direction and to ensure the implementation of a process that is consistent with federal law. We have shared some preliminary thoughts with Department staff regarding the rights of people with disabilities, and by copy of this letter we are providing our additional comments on the Draft Protocol.

As you know, certain federal laws apply to the provision of services by both public and private hospitals and other healthcare providers.[1] To promote compliance with federal law and fair and equal

[1] 42 U.S.C. 12132, Americans with Disabilities Act, Title II; 42 U.S.C. 12182, Americans with Disabilities Act, Title III; 29 U.S.C. 794(a), Section 504 of the Rehabilitation Act; and 42 U.S.C. 18116(a), Section 1557 of the Affordable Care Act.

North Carolina's Protection and Advocacy System
3724 National Drive
Suite 100
Raleigh, NC 27612
919-856-2195
877-235-4210
919-856-2244 fax
TTY users, dial 711
www.disabilityrightsnc.org

treatment of individuals with disabilities, the National Council on Disability (NCD)[2] and the Consortium for Citizens with Disabilities (CCD)[3] have proposed important principles for the delivery of care:

> 1) that the ADA and Section 504 require government decisions regarding the allocation of treatment/life-saving resources to be made based on individualized determinations, using current objective medical evidence, not generalized assumptions about a person's disability;
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> 2) that the ADA and Section 504 prohibit treatment allocation decisions based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living;
>
> 3) that the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person with a disability has a lower prospect of survival;
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> 4) that the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person's disability will require the use of greater treatment resources; and
>
> 5) that a person is "qualified" for purposes of receiving COVID-19 treatment if he or she can benefit from the treatment (that is, can recover) and the treatment is not contraindicated.[4]

We have shared with your staff recent U.S. HHS OCR complaints from other states related to scarce resource allocation policies that violate these principles, as well as analysis prepared by Professor Samuel Bagenstos addressing the legal imperatives associated with scarce resources in the context of disability.

Applying these principles and applicable law, we believe that the core imperatives with regard to the Draft Protocol are the need for:

> 1. an express directive that medical staff must not rely on disability as a factor in decision-making where the individual's disability does not preclude recovery from COVID-19;
>
> 2. a requirement that scarce resource allocation criteria must only relate to COVID-19 survive-ability and not perceived "quality of life" or ability to independently perform ADLs; and
>
> 3. elimination of references to specific disability categories as *per se* bars to access to scarce resources.

Specifically, we are asking that the Draft Protocol be revised in the following ways:

1. Inclusion of express non-discrimination language

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[2] See, Letter of National Council to Roger Severino, Director, Office for Civil Rights, U.S. Department of Health & Human Services, March 18, 2020, available at https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr.

[3] CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

[4] See, Consortium of Citizens with Disabilities, letter to Secretaries of EOHHS and the Office of Civil Rights, March 20, 2020, available at http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf.

The following provision from the Arizona Crisis Standards of Care Plan offers a simple but important principle:

> In a public health emergency, to the extent possible, similarly-situated individuals and groups will be treated in similar ways. (**A disability in and of itself is NOT a criteria for decision-making**).

Arizona Crisis Standards Care Plan ("Arizona Plan"),

https://www.azdhs.gov/documents/preparedness/emergency-preparedness/response-plans/azcsc-plan.pdf, p. 87. (emphasis added)

Consciously or not, many in our society reflexively devalue the lives of people with disabilities. Given the potential for high-stress decision-making in the context of the delivery of medical care during the COVID-19 crisis, we believe it is critical that the Department and/or the Governor make a clear statement about the equal value of life regardless of disability.

2. Clarification that consideration of prognosis relates only to recovery from COVID-19

There are several references in the current Draft Protocol to comorbidities that could fairly be construed as permitting consideration of conditions unrelated to the COVID-19 infection that would be discriminatory and in violation of federal law. For example, the Draft Protocol indicates that an individual could be excluded from life-saving but scarce care based on "confirmed severe irreversible cognitive impairment," and "[o]ther condition[s] with an expected poor prognosis." *Draft Protocol*, p. 6. Similarly, some exclusions are based on the individual's need for assistance with ADLs. *Id*. These considerations are not directly linked to whether an individual would survive COVID-19; they create the considerable likelihood that individuals will be excluded from life-saving treatment based on subjective judgments about whose life is worth living.

Rather than rely on judgments that relate to perceived quality of life, decisions must be confined to questions of survival, or survive-ability. If an individual has reasonable prospect of *surviving COVID-19*, they must be eligible for life-saving treatment irrespective of any other disability or medical condition.

As one commentator noted in discussion with the Advisory Group, race, class, and geography play strong roles in certain conditions because of inequities inherent in current systems. These include diabetes, hypertension, and some cancers. Applying a standard of survive-ability rather than reference to the need for assistance with ADLs, or other factors that are typically perceived as relating to quality of life, would go a long way toward avoiding further harm to those already disadvantaged by current health and healthcare inequities. Further, because of NC's over-reliance on congregate settings to provide necessary supports and services to people with disabilities, people with disabilities are likely at increased risk of infection. To reinforce that bias with a refusal to provide treatment is particularly inhumane.

In addition to the non-discrimination language noted above, the following language from the Arizona Plan captures an appropriate intention, and we request inclusion of this or similar language:

> Public health responses and allocation of scarce resources (such as vaccines, ventilators, or evacuation assistance) may not be based on factors unrelated to health status and emergency response needs. Impermissible factors include, but are not limited to: race, gender, ethnicity, religion, social status, location, education, income, ability to pay, disability unrelated to prognosis [for recovery from COVID-19], immigration status, or sexual orientation.

Arizona Plan, p. 88.

3. Elimination of categorical disqualification

Certain specific conditions are considered disqualifying for intervention in the Draft Protocol. We support the position taken by several commenters during discussions with the Advisory Group who advocated for reliance on the objective scoring (S.R.A.S.) process and the elimination of categorical disqualification based on diagnosis. As noted above, these categories relate, at least in part, to questions of perceived quality of life. To the extent the Advisory Group concludes that certain conditions reduce the likelihood that an individual would recover from COVD-19 (or the use of a ventilator), such a factor should be part of the S.R.A.S. calculation, and not a *per se* disqualification from life-saving treatment. This would be consistent with the use of more objective medical criteria in the current S.R.A.S. for determining survive-ability.

In addition to employing more objective connection to COVID-19 survival, the elimination of categorical disqualification would reflect a commitment to comply with federal law – which must be made explicit – and a clear directive that the existence of a disability is not a basis for decision-making in the context of who receives life-saving interventions.

We welcome any questions and look forward to continued cooperation as we address the pandemic's effects on people with disabilities. Our Director of Public Policy, Corye Dunn, is available to work with you and your team throughout this process.

Regards,

Virginia Knowlton Marcus

CEO

Cc: Adam Zolotor

Benjamin Money

Kody Kinsley

Lisa Corbett