

August 10, 2020

Lori Shibinette

Via Email: SDMAC@dhhs.nh.gov and Mail

Commissioner

Department of Health and Human Services

129 Pleasant St

Concord, NH 03301

Re: DRAFT New Hampshire State Triage Committee Crisis Standards of Care Clinical Guidelines Dated June 23, 2020

Dear Commissioner Shibinette,

Thank you for this opportunity to submit comments on New Hampshire's Crisis Standards of Care Clinical Guidelines on behalf of the organizations named below. Together, we represent thousands of people with disabilities and rare diseases across New Hampshire and the United States.

It is critical that the state's plans to address a crisis incorporate a variety of perspectives. As we have seen in other states, the failure to solicit the thoughts and ideas of people with disabilities and other vulnerable groups in developing crisis plans can lead to direct and indirect discrimination against people with disabilities.

We write to express concerns about the most recent draft of the state's Crisis Standards of Care Clinical Guideline, published on June 23, 2020, specifically in the following four areas:

1) Oversight

DHHS via the SDMAC must review and assess all hospital plans to ensure they comply with both the Crisis Standards of Care Plan and Clinical Guidelines, as well as the U.S. Department of Health and Human Services Office of Civil Rights (OCR) [March 28th bulletin](#) on Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19). DHHS must ensure that all plans comply with these standards and that no hospital or healthcare provider plan discriminates

against people with disabilities, minority groups, the elderly or any other specific class of people.

According to the Center for Public Representation, “Without a binding, statewide crisis plan, the exercise of medical discretion across hospital systems will be largely unchecked, unguided, and subject to wide variation. The unavoidable result is highly subjective decision-making, undermining public trust and placing even greater responsibility and stress on treating professionals.”ⁱ

New Hampshire is a small state and it is likely that the state could face a crisis that impacts multiple facilities in a region or the state as a whole. While it seems that New Hampshire’s resources are sufficient at the moment, this could change at any time and we must be prepared. If there is a surge of COVID-19 cases, the state could be required to actively oversee the transfer of resources and patients across the state.

Consistency in individual hospital practices will make this difficult process easier. This includes assessing how hospitals and other facilities are training staff about their plans and the processes to make these critical decisions. Now is the time for DHHS to address any concerns or issues with specific facility plans. Waiting until we are in the midst of a crisis can only lead to more problems and potential discrimination.

Furthermore, we strongly believe that the work of this committee should continue beyond the development of the initial Crisis Standards of Care Plan and Triage Guidelines. As noted above, we believe that the committee should help DHHS assess hospital plans to identify any barriers to care and coordinate the publication of state and hospital plans to the general public. If New Hampshire does face a crisis, the committee must be prepared to assess our response to identify barriers, challenges and opportunities to improve.

We understand that each hospital must assess its specific resources, and other factors, but DHHS must take final responsibility for New Hampshire’s crisis planning and implementation, including ensuring that individual hospital and other healthcare provider plans comply with these standards.

2) Transparency

The state has attempted to be transparent in the work of the SDMAC and its committees as they work to develop the New Hampshire Crisis Standards of Care Plan, which is appreciated.

However, there also should be an expectation that hospitals and other healthcare providers are transparent in their individual plans. The state should provide links to all individual hospital and healthcare provider crisis plans on the SDMAC website.

Input from stakeholders, including other hospitals, disability advocacy organizations and other patient advocacy organizations will help to ensure plans are free from discrimination and can help increase the public trust in this process if the Crisis Standards of Care Plan must be implemented.

Additionally, a copy of the crisis plan, in accessible language, should be provided to patients entering a hospital for crisis care when the plan is in effect or is close to being implemented. It must also be easily accessible on the hospital's website and provided to any member of the public upon request.

Finally, if it appears that the state is approaching a crisis, DHHS must actively notify Area Agencies, Elderly and Adult Services Case Management Agencies and Community Health Centers so that they can help to educate patients and their families about their rights and this process.

3) Accessibility

Directly related to transparency is accessibility. It is not sufficient that hospitals are transparent in their plans if they are so complex that they cannot be understood by the general public. Hospitals must develop and distribute accessible education materials related to their plans for the general public. These plans must clearly explain the process for allocating resources, removing resources and appealing any decisions.

In addition, materials must be designed to empower patients to ask questions and advocate for themselves throughout the crisis. When patients cannot communicate their wishes, guardians

and families must be involved. The guidelines must recognize that families need time to make decisions and allow sufficient time, even in a crisis scenario.

4) Diversity

A diversity of perspectives is critical to the development of appropriate crisis standards of care. While we appreciate the current members of the committee, you must expand the membership to include additional people with a diversity of disability experiences and people of diverse racial and ethnic communities. Additional members can provide important perspective from communities that require significant medical monitoring and intervention to thrive or have been shown to be disproportionately affected by the current COVID-19 crisis.

Thank you for this opportunity to comment.

Sincerely,

ABLE NH (Advocates Building Lasting Equality)

Brain Injury Association of New Hampshire

Community Bridges

Community Crossroads

Community Partners

Community Support Network, Inc.

Council for Youths with Chronic Conditions (CYCC)

Cure SMA

Disability Rights Center - NH

Easterseals NH

EngAGING NH

Epilepsy Foundation New England

Gateways Community Services

Granite Case Management

Granite State Independent Living

Lakes Region Community Services

Legal Advice & Referral Center

Life Coping

Medical Care Advisory Committee

National Organization for Rare Disorders

New England Chapter of Paralyzed Veterans of America

New England Hemophilia Association

New Hampshire Rare Action Network

NH Council on Developmental Disabilities

NH Family Voices

NH Poor People's Campaign

Northeast Deaf & Hard of Hearing Services

Parent Information Center

PathWays of the River Valley

ⁱ <https://www.centerforpublicrep.org/wp-content/uploads/Updated-evaluation-framework.pdf>