



Maine Developmental Disabilities Council

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April 14, 2020

Dear Dr. Shah,

I am writing to you on behalf of the Maine Developmental Disabilities Council. DD Councils are in every state and territory. We were established in federal law nearly 50 years ago when the wholesale failure of medicine and social services towards people with Developmental Disabilities (DD) in institutions came to light. DD Councils are charged to ensure the systemic participation of individuals with developmental disabilities and their family members in the development of laws and policies impacting them.

I am writing to you today because, like everyone else, people with DD and their families are afraid. In addition to fears shared by the community at large, Mainers with DD are at high risk. They are more likely to have challenges with communication or comprehension which significantly impedes access to appropriate healthcare. They are more likely to have chronic health conditions. They are more likely to have physical or cognitive barriers that compromise their ability to comply with public health recommendations. Approximately 1,800 adults with DD live in congregate living settings with staff support, and several thousand more receive in-home services from outside staff. In addition to that immediate physical risk, people with DD live with the fear that public responses to widespread emergencies will leave them behind, sometimes to die, as they did during Hurricane Katrina.

I am writing to you today to ask you to address those fears by

1. **Providing statewide guidance regarding hospital visitor policies**

Some individuals, as a result of cognitive, communication, or behavioral challenges resulting from their developmental disability, require a support person to access health care. Families have been told that some hospitals in Maine have said that they will absolutely not be allowed to accompany the patient who needs that accommodation.

Below is a sample of hospital policies:

- Extraordinary circumstances (one person at a time), if presence is necessary for communication with care team or patient support ((e.g., patient with disabilities). The determination may be made only by attending physician or designee, and record in the medical record, if feasible)
 - All Maine Health Hospitals, except Spring Harbor Hospital
 - Maine General Hospital
 - MidCoast Hospital
- Patients with disruptive behavior, where a family member is key to their care, may have one visitor. AND Patients who have altered mental status or developmental delays (where caregiver provides safety) may have one visitor. [NOTE: Patients that need assistance with communication or comprehension by a caregiver (family or direct service provider) is not permitted.)
 - All of Northern Light Healthcare
- No visitors permitted due to disability and communication.
 - Central Maine Healthcare hospital,
 - Bridgton Hospitals,
 - Rumford Hospital
 - Northern Maine Medical Center
- Visitors must be free of flu like symptoms and be older than 12.
 - Calais Regional Hospitals
 - Cary Medical Center

As you can see, there is a wide variety of policies. We are very concerned that this patchwork approach could contain bias, be discriminatory, and prevent patients access to appropriate healthcare as individuals with developmental disabilities will not have the support with communication or comprehension that they need to access appropriate care.

2. **Preventing Rationing of Care**

While healthcare discrimination is illegal, access is often not equitable. Please see some very recent examples of that in the attached letter by Speaking Up for Us, the State's self-advocacy network, that was sent last week to the Governor expressing their concerns about potential inequity of care during this crisis.

We ask that you clearly state that hospitals and health care providers must not put into place protocols or make decisions based on “stereotypes, assessments of quality of life, or judgements about a person’s relative ‘worth based on the presence or absence of disabilities.” See Department of Health and Human Services Office for Civil Rights in Action. "BULLETIN: Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)" at https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uQLIPxDR0eiAizAQ8Q-XwhBt_0asYiXi91XW4rnAKW8kxcog

Please issue guidance to Maine's hospitals that allows people with I/DD to receive appropriate healthcare by ensuring that they are able to have communication and comprehension support provided by knowledgeable, trusted people such as family or other caregivers. The New York Department of Health "COVID-19 Updated Guidance for Hospital Operators Regarding Visitation" addresses this issue:

https://coronavirus.health.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_041020-002.pdf.

Dr. Shah, thank you for your tireless work to protect and promote the health of Mainers during this unprecedented time. We appreciate your leadership, expertise and your sense of humor. The Maine Developmental Disabilities Council stands ready to provide input and support that would be helpful to ensuring that all Mainers are supported, including people with DD, during this time of COVID-19.

Please don't hesitate to contact me at any time.

Sincerely,

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