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April 17, 2020

Via Electronic Mail

Monica Bharel, MD, MPH
Department of Public Health Commissioner

Re: Hospital Visitation Policies for Persons with Disabilities

Dear Commissioner Bharel:

We appreciate the Administration's tireless work during the COVID-19 pandemic, including continued work on behalf of people with disabilities. We write to urge the Department of Public Health to adopt a statewide policy on hospital visitors during the COVID-19 emergency that includes reasonable accommodations for people with disabilities who may require a support person to stay with them during emergency room visits and hospitalizations.[1]

We have serious concerns about people with disabilities who need assistance in the hospital setting being prevented from having a support person with them. At the present time, hospitals in Massachusetts are permitted to develop their own visitor policies. In some instances, those policies exclude guardians and support persons of people with disabilities from participating in their care and/or assisting with their communication needs.

Even in this pandemic, people with disabilities who need communication or behavioral supports in hospital settings retain their rights to reasonable accommodations under the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. The U.S. Department of Health and Human Services' Office of Civil Rights issued a Bulletin on

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[1] We also recommend the revised Massachusetts Crisis Standards of Care specifically reference hospitals' affirmative obligation to make reasonable modifications to hospital policies when necessary to accommodate a person's disability. *See, e.g.,* Advocates letter to Governor Baker and state officials, dated April 9, 2020, available at https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Ltr-Admin-on-MA-crisis-standards.4.9.20.pdf

March 28, 2020 emphasizing the need for hospitals and other covered entities to follow federal disability and other civil rights laws during this pandemic. The Bulletin specifically states that "government officials, health care providers and covered entities should not overlook their obligations under federal civil rights laws" to address the needs of individuals with disabilities, including individuals with impaired speaking and sensory skills, and to provide effective communication with individuals with disabilities.[2]

To assist the Department, we request that Massachusetts immediately issue a directive stating that hospital visitation policies restricting or barring visitors must include an exception with language similar to the following:

> Patients with disabilities who need assistance due to the specifics of their disability may have one designated support person with them. This could include specific needs due to altered mental status, intellectual or cognitive disability, communication barriers or behavioral concerns. If a patient with a disability requires an accommodation that involves the presence of a family member, personal care assistant or similar disability service provider, knowledgeable about the management of their care, to physically or emotionally assist them during their hospitalization, this will be allowed with proper precautions taken to contain the spread of infection.[3]

Additionally, consistent with the New York policy issued on April 10, 2020[4] we recommend the Massachusetts policy allow the person with a disability to designate two support people; however, only one support person could be present at a time. Given the demands on the support person, we believe the New York approach is reasonable.

To illustrate the importance of this issue further, we have gathered personal stories from people with disabilities and family members of people with disabilities who would be harmed if the above accommodations were not provided. Below are three examples of many we received.

> My name is Jonathan Huggon and I am 27 years old. I have an active life that includes my photography, volunteering at Taunton city hall, and spending time with family and friends. I was diagnosed with quadriplegia after becoming ill with viral meningitis at two weeks old. I am dependent for my physical needs and cannot speak verbally. I am very capable of thinking for myself, however, because I cannot speak verbally people who do not know me assume I cannot understand. My parents are my healthcare proxies and help me to communicate my thoughts and desires in difficult situations. I have been hospitalized numerous times for surgeries and emergency care, but either my mother or father were present at all times. The medical professionals who have cared for me have been most thankful for my parents/family's assistance as it helped to provide the treatment my body needed. **Should I become ill in the**

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[2] *See* https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf. *See also* Coronavirus Aid, Relief, and Economic Security (CARES) Act, section 3715 (permitting state Medicaid programs to fund direct support professionals trained to assist people with disabilities with activities of daily living to provide such services in hospital settings).

[3] *See* Rush University Medical Center policy found at https://www.rush.edu/patientsvisitors/covid-19-resources/rush-coronavirus-covid-19-patient-and-visitor-updates

[4] https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10. 20.pdf

> **future and need to be hospitalized, without the assistance of my family my health will be in grave danger.** (emphasis in original)
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> *Submitted by Jonathan Huggon with assistance.*
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> When I had my hernia operation my mom and staff were right beside me all of the way. I was experiencing pain. My mom knew I was in pain…The reason it is important to have someone who knows you go to the hospital with you is because the staff at the house know our baseline which means how we act normally. If we act somewhat out of baseline staff can pick that up very easily. It makes people feel very much more relaxed to have staff and family there with them. Much calmer because it can be a scary experience. How could a stranger know what we are feeling? A stranger asks us if we need help but once staff comes they really know what we need.
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> *Submitted by John Michael Mullaly, Massachusetts Advocates Standing Strong*
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> My son, Tyler, is 20 years old and has a very rare genetic condition that results in a severe intellectual disability. He has some receptive language and communicates basic needs on an iPad-like device, but he's very limited in what he can express and has a very high level of anxiety in unfamiliar settings. I cannot express strongly enough how important it is for him to have a person he knows with him in the hospital. And not just for his own needs, but also for those of the providers who will be trying to care for him. In past hospital stays, he has taken IVs out of his arm, fought against simple procedures, and escaped from his bed regardless of what tubes are hooked up to his body. If a parent or familiar caregiver is with him, none of these would happen. Even aside from the mental stress he experiences, the work and attention it would take for nurses to keep him in his bed and treat him would be completely untenable. There are really only three choices: take up a nurse's time to stay with him at all times (and still struggle), drastically sedate him for the entire stay, or simply allow a caregiver to accompany him during a hospital stay. Given the cost of healthcare and the shortage of providers at this time of crisis, it seems to me that the answer is quite obvious. Not to mention basic humanity.
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> *Submitted by Julie McKinney.*

We appreciate the Administration’s, as well as the state agencies’, tireless work during this public health emergency. Please feel free to contact Marlene Sallo at 617-315-4592 or msallo@dlc-ma.org if you have questions regarding this matter or if you require additional information. Thank you for your prompt attention to this matter.

Sincerely,

Marlene Sallo, Executive Director
Hillary Dunn Stanisz, Senior Attorney
Disability Law Center

Kathryn Rucker, Senior Attorney
Center for Public Representation

Janet Laperle, Chairperson
Brian Kremer, Statewide Coordinator
Massachusetts Advocates Standing Strong

Sandra Heller, Co-Chair
O. Sophia Johansson, Co-Chair
Massachusetts Families Organizing for Change

Leo Sarkissian, Executive Director
The Arc of Massachusetts

Daniel Shannon, Executive Director
Massachusetts Developmental Disabilities Council

Cc: Governor Charles Baker
Secretary Marylou Sudders
Daniel Tsai, Acting Secretary, EOHHS