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Sent via Electronic Mail and U.S. Mail

April 30, 2020

The Hon. Robert R. Neall, Secretary of Health
Office of the Secretary
Maryland Department of Health
Herbert R. O'Connor State Office Building
201 West Preston Street
Baltimore, Maryland 21201

Sent via email and first class mail to robert.neall@maryland.gov

Re: **Hospital Visitation Policies for Individuals with Disabilities**

Dear Secretary Neall:

I write on behalf of Disability Rights Maryland (DRM), the state's designated protection and advocacy system. I am urging you to take swift action to provide statewide guidance to hospitals and health care facilities concerning visitors and other reasonable accommodations for people with disabilities during the COVID-19 emergency. It is imperative that explicit exceptions be made to the many restrictive hospital and health care facility visitor policies in order to allow individuals with disabilities to have with them a support person when needed due to the nature of their disability.

DRM received a call from the sister of a young woman with Autism Spectrum Disorder with Intellectual Disability who communicates mostly non-verbally and recently was tested for COVID-19 after being exposed to someone who tested positive. Thankfully, the young woman tested negative for the virus so far; however, the caller is very worried that her sister is at high risk of serious health consequences should she contract the virus because of an underlying medical condition. The caller's sister was hospitalized last year with pneumonia, the symptoms of which were not immediately recognized due to the nature of her disability. The pneumonia developed into Acute Respiratory Distress Syndrome (ARDS), which left her in critical condition, requiring intubation and a coma. The caller, along with her elderly mother and the young woman's one on one 24/7 direct support professional assisted her through that very critical situation by helping her communicate her values and medical decisions to health care professionals. Her disability and the seriousness of her condition required one of the three individuals to stay by her side 24/7 to provide support for communication and behavioral challenges while she was sick at the hospital.

As the novel COVID-19 outbreak has led to widespread No Visitor Policies at Maryland hospitals and health care facilities, this caller and others are very concerned about the possibility of loved ones with disabilities being refused a support person at the patient's bedside, visitors, or other reasonable accommodations in the current environment.

This concern is highlighted by some Maryland visitation policies¹ that lack exceptions for individuals with disabilities who need a support person to be present during hospitalization, or exclude some people with disabilities who need the support, including for reasons related to their disabilities, such as health care decision making, or emotional and/or behavioral support.

Individuals with disabilities who need communication, behavioral, or decision making supports in hospital situations retain their rights to reasonable accommodation and modifications of policies, procedures and practices under federal law, including the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act (ACA), even in a pandemic.

DRM reviewed several policies from other states and hospitals. We propose that the Department of Health immediately issue a mandatory directive stating that hospital and health care facility visitation policies restricting visitors must include an exception with language similar to the following:

Patients with disabilities who need assistance due to the specifics of their disability(ies) 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, or another person they choose knowledgeable about the management of their care, to physically or emotionally assist them during their hospitalization or treatment, this will be allowed with proper precautions taken to contain the spread of the virus.

For hospitalized patients, especially with prolonged hospitalizations, the patient or family/caregiver may designate three support people; but only one support person

¹ See, e.g., MedStar Health, accessed April 30, 2020, *Temporary Visitor Restrictions and Guidance During COVID-19*, available at: <https://www.medstarhealth.org/mhs/about-medstar/covid-19-info/visitor-restrictions-and-guidance-during-covid-19/> (providing one of its exceptions only for "one visitor/caretaker for 'developmentally delayed' or 'severely agitated patients with dementia' or "one visitor if indicated by patient's provider to support patient rehabilitation needs"); University of Maryland Medical Center, *Temporary Visitor Restrictions*, accessed April 30, 2020, available at: <https://www.umms.org/ummc/coronavirus/temporary-visitor-restrictions> (providing no exception(s) for people with I/DD or other disabilities needing support); Johns Hopkins University Hospital, *Revised Johns Hopkins Medicine Visitor Restriction Guidelines Related to COVID-19*, accessed April 30, 2020, available at: <https://www.hopkinsmedicine.org/coronavirus/visitor-guidelines.html#policy> (providing one of its exceptions for "[o]ne visitor if the patient's care team has requested the visitor to be a part of scheduled family training for patients with rehabilitation or for help with cognitive needs, with approval from the Johns Hopkins Medicine care team.")

may be present at a time. This restriction must be explained to the patient and support person in plain terms, upon arrival or ideally, prior to arriving at the hospital. For patients currently hospitalized, hospital staff should ensure that a procedure is implemented to train staff and alert current patients of the exception and to ensure patients fully understand this restriction and exception, allowing them to decide who they wish to identify as their support people.

This is consistent with Maryland's recognition of supported decision making as a reasonable accommodation in the health care setting², and guidance from other states and medical experts.³

Your diligent work on behalf of individuals with disabilities and all Marylanders is sincerely appreciated. Please do not hesitate to contact me at (443)692-2477 or CaseyS@disabilityrightsmd.org if you have questions or would like additional information. Thank you in advance for your consideration of this matter.

Sincerely,

/s/ Casey Shea

Casey Shea, Esq.
Staff Attorney
Disability Rights Maryland

cc: Carol Beatty, Secretary of Disabilities, Maryland Department of Disabilities
Kathleen Ellis, Esq., Office of the Attorney General

² Maryland has codified, under Md. Code Ann., Insurance § 27-915, that Marylanders with disabilities may require support in making and receiving certain medical treatment and that this support should be provided as a reasonable accommodation. In accordance with Americans with Disabilities Act (ADA), this provision recognizes that people with disabilities may require the support of others who they trust to comply with certain medical treatment. Providing this support is recognized as a reasonable accommodation, and does not justify denying the person treatment or care.

³ See American Academy of Developmental Medicine & Dentistry, Hospitalized Patients & Designated Support Staff Policy Statement, available here:

<https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5e9e1cbefc832d0a6866fed4/1587420352080/Visitation-PolicyStatement.pdf> (April 2020) (recommending that hospitals provide reasonable accommodations in their visitors policies for patients, including people with intellectual and developmental disabilities, who need support from family, community agency personnel, or other designated caregivers while in the hospital); see also, e.g., New York Department of Health, Health Advisory on COVID-19 Updated Guidance for Hospital Operators Regarding Visitation, available here:

https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf (April 10, 2020)(requiring hospitals permit a patient support person at the patient bedside for "[p]atients for whom a support person has been determined to be essential to the care of the patient (medically necessary) including patients with intellectual and/or developmental disabilities and patients with cognitive impairments including dementia") and Oregon Health Authority, REVISED COVID-19 Guidance for Entry into Acute Health Care Facilities, available here:

<https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le2282.pdf> (providing an exception for patients who need assistance due to their disability, including needs due to altered mental status, intellectual or cognitive disability, communication barriers, or behavioral concerns) (April 23, 2020).