August 26, 2020

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

The Honorable Carol Beatty, Secretary
Maryland Department of Disabilities
217 E. Redwood Street, Suite 1300
Baltimore, Maryland 21202

Sent via e-mail to: robert.neall@maryland.gov and carol.beatty@maryland.gov.

RE: Access to disability support personnel in health care facilities

Dear Secretary Neall and Secretary Beatty:

We, the undersigned, submit this letter to request that the State of Maryland take further action to ensure that visitor and reasonable accommodation policies are adopted by health care facilities throughout the state. We believe further action is needed to ensure that health care facilities do not discriminate against patients and consumers with disabilities.

We very much appreciate the first step the State took to provide a directive to hospitals concerning these issues. This provided an avenue for people with disabilities to avoid discrimination and access the needed support, communication, treatment and care they require while hospitalized. However, we believe more should be done on this vital issue and ask for consideration of the following concerns and recommended actions:

1. Maryland’s directive does not apply to all health care facilities, such as Nursing Facilities and outpatient health care providers. Many such facilities have a blanket no-visitor policy resulting in discrimination against people with disabilities, some who need communication, emotional, decision making and other support to gain equal access to care. The current "Maryland Department of Health Guidance for Relaxation of Restrictions Implemented During the COVID-19 Pandemic – Nursing Homes” is silent about the rights of Nursing Facility residents with disabilities to disability support persons; however, visitor restrictions are in effect¹ and have been widely reported.²

¹ https://phpa.health.maryland.gov/Documents/MDH_Relaxing_Restrictions_Nursing_Homes.pdf
RECOMMENDATION: Amend Maryland’s Disability Support Directive to provide clear non-discrimination expectations for all health care facility providers in Maryland.

2. Some hospitals have been slow to amend their policies and some have fallen short in practice to comply with the State’s directive and our disability rights laws. For example:
   - Disability Rights Maryland has had to intervene in five recent cases where hospitals refused to allow support persons to assist patients with disabilities, AFTER the state directive had been issued. In two cases the individuals with disabilities died within days of their rights being enforced. The consequences for those involved are heart wrenching.
   - At least two facilities do not provide an exception for disability support persons to their no visitor policy and have not changed their policies since the state directive was issued.³
   - One other facility lists no exception to its no-visitor policy for people with disabilities needing support persons.⁴
   - At least one facility has prohibited access to visitors for patients who tested positive for COVID-19; and another facility provides access to support persons as an exception to the no visitor policy but then raises questions as to the applicability for patients with disabilities who test positive needing support personnel by providing that “[i]n inpatient facilities and emergency department, VISITORS will NOT be permitted for COVID positive and/or [Patients Under Investigation for COVID-19] patients.”⁵
   - One hospital does not post its restricted visitor policy on its website.⁶
   - In two of the cases in which DRM had to intervene, the two facilities had only allowed support persons in the hospital for two hours when the people with disabilities needed the support ongoing.
   - Two facilities in cases in which DRM had to intervene claimed that their hospital staff were providing the support that the person’s designated support personnel would provide as grounds for denying the disability support personnel when the hospital personnel was not able to provide the vast majority of the support needed.

⁴ See https://www.peninsula.org/visiting-covid-19-changes (accessed online August 26, 2020)
⁵ See Greater Baltimore Medical Center, https://www.gbmc.org/policy (policy dated March 29, 2020, accessed August 6, 2020; new policy posted on August 7, 2020 allows approved visitors for patients with a disability when they meet certain requirements, but the same exception is not listed under pg. 3 of the policy that prohibits visitation for those suspected of confirmed to have COVID-19 except for a one-time two-hour visit for COVID positive patients who are at the end of life.). The U.S. Department of Health and Human Services (HHS) Office of Civil Rights (OCR) recently announced on July 21, 2020 a resolution with Prince George’s County Hospital Center of the University of Maryland Medical System, including to modify their policies to allow protection of people with disabilities who need support persons as they receive care; previously the policy prohibited some patients with disabilities – including those who tested positive for COVID-19 – from having support persons present during their hospital stay.
After DRM intervened explaining the role of the support person, one hospital allowed access; in another case, the person was denied access and discharged from the hospital before intervention.

- One hospital system allows only one disability support person when approved by hospital Vice President of Medical Affairs and/or Chief Nursing Officer when many people with disabilities need more than one person designated who can rotate in order to provide the needed support. Another large hospital system has just one or two individuals at each hospital to review all proposed visitor exceptions, which has led to initial denial and delayed decisions about whether support personnel will be granted access.

RECOMMENDATION: Provide an expedited mechanism to (1) review disability support personnel access and other disability accommodation requests and (2) to review health care facility policies and enforce the Secretaries’ directive.

3. Individuals should be able to identify their rights as set forth in the Disability Support Directive. Unfortunately, information about the directive and the directive itself is not readily available on the Department of Health’s main website or COVID-19 webpage. Most people also do not know whom to contact at health care facilities that is familiar with the Disability Support Personnel Directive and trained on the Americans with Disabilities Act and disability rights laws. Many also do not know that the Office of Health Care Quality (OHCQ) can investigate complaints of violations of the Department’s directive.

RECOMMENDATIONS: (1) Post the directive clearly on MDH’s website and COVID-19 webpage; (2) provide notice and contact information related to the authority of OHCQ to investigate allegations of health care facility non-compliance with the directive; and (3) update the directive to require health care facilities to list a contact point familiar with Americans with Disabilities Act (ADA) and other disability support personnel legal requirements to whom questions or violations of the directive may be addressed.

4. Maryland’s directive and state policy need additional directions so that health care facilities and consumers have clear expectations on their respective obligations and rights. On May 15, 2020, six national disability rights groups published an evaluation Framework guide to help stakeholders to determine whether state and health care facility no-visitor policies unfairly discriminate against patients with disabilities.

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8 https://pxjournal.org/cgi/viewcontent.cgi?article=1496&context=journal (see pg. 124).
RECOMMENDATION: Use the Framework to address the following elements to create clear expectations and notice of rights in the state directive and policy FAQs:

a. Disability support personnel must be allowed for patients with any type of disability who need them. The State’s “Frequently Asked Questions” document published on June 2, 2020, provides that “the types of patients that a support person would be appropriate for in a hospital setting include but are not limited to: Patients with intellectual or developmental disabilities, physical disabilities or limitations, or neurocognitive disorders.” We urge that the directive and policy FAQ specifically provide that “disability support persons must be allowed for patients with any kind of disability who need them, including patients with physical, communication, mental health, sensory, cognitive, and developmental disabilities.”

b. The directive must make clear that patients with disabilities – regardless of their COVID-19 status – are entitled to access in-person disability support persons.

c. The directive should require facilities to clearly advertise and post notice of the directive at patient entry points in every facility, on the facility’s website, and be provided to the patient at the time services are scheduled or initiated.

d. The directive should state that it is available in different languages and formats to ensure access to individuals who do not speak English and those individuals with vision impairments.

e. The directive or policy FAQ should encourage facilities to provide appropriate Personal Protective Equipment (PPE) to support persons as instructed by the facility for the duration of the visit. If the facility does not have PPE for the support person, the directive should provide that PPE supplied by the support person that the facility finds adequate may be used.

f. The directive should be clear that a support person is different from a “visitor,” because access to a support person is a reasonable accommodation under federal law that is meant to ensure equal access to medical care. The directive should identify that reasonable accommodations and modifications of health care facility no-visitor policies, procedures and practices are required under Titles II and III of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act.

g. Clarify in the directive and policy FAQ that a support person may be applicable for many reasons and not limited, as suggested by the Maryland policy FAQs, to “when the patient requires services for communication and behavioral stabilization.” For example, support personnel can also provide critically important physical and emotional support necessary for the patient to receive equal access to the treatment.

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10 “Access to Support for Patients with Disabilities in Hospital Settings Frequently Asked Questions (FAQ),” June 5, 2020, available at:
h. The directive should state that a designated support person includes any individual knowledgeable about the needs of the person with the disability and who are able to assist them, and thus include a person’s natural support system – including, for example, close friends – and not be limited to service providers and family members.

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

Sincerely,

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