

July 17, 2020

Sent via email

The Honorable Ralph Northam
Office of Governor
P.O. Box 1475
Richmond, VA 23218

RE: Reasonable access to disability support personnel in health care settings

Dear Governor Northam:

We, the undersigned, submit this letter to request that the Commonwealth of Virginia take action to ensure that “no-visitor” policies recently adopted by health care facilities throughout the state do not discriminate against patients with disabilities during the COVID-19 public health emergency.

The absence of clear state-level guidance and policy on this issue has led to facilities unlawfully denying patients with disabilities access to in-person supports they may need to equitably access health care, in violation of Titles II and III of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (Section 504), and Section 1557 of the Affordable Care Act (ACA). To prevent further legal violations and to adhere to recently adopted guidance from the U.S. Department of Health and Human Services Office for Civil Rights on this topic, we ask that you direct the appropriate agencies to adopt clear guidance as soon as possible reminding health care facilities of their legal requirements to permit safe access to disability support personnel when necessary for a patient with a disability to access and benefit from health care.

Currently, there are a myriad of policies and practices governing patient access to visitors and support personnel in health care settings across Virginia. In the absence of clear state guidance on this topic, including a reminder that the ADA, Section 504, and Section 1557 of the ACA remain in effect, many health care facilities have adopted policies that either discriminate against patients with disabilities on their face, or have the effect of doing so in practice. These policies are routinely used to prevent patients with disabilities from accessing the in-person supports they require to communicate effectively with their health care providers or to otherwise benefit from medical treatment provided to patients without disabilities, violating their civil rights and jeopardizing their quality of care.

Three recent examples of discrimination against Virginian patients with disabilities resulting from no-visitor policies in the Commonwealth are highlighted below:

- J.M., a 29-year-old man diagnosed with autism who has 24-hour support needs for his anxiety, communication, and sensory disabilities, was hospitalized in February for multiple medical conditions. His family paid for these necessary disability personnel to support him in the hospital 18 hours a day, and his mother covered the remaining 6 hours a day. After the hospital adopted a no-visitor policy due to COVID-19 in March, J.M.'s support personnel were asked to leave. However, the hospital's policy continued to allow one adult visitor for "pediatrics, labor and delivery, NICU, Mother/infant, Pre- and post-surgery (patient advocates), Med Surg/Step Down, End of life", clear exceptions, but not for patients with disabilities.

Without his necessary disability support personnel, J.M. pulled out his feeding tube three times in four days and grinded his teeth so hard that a double crown was removed. Replacing feeding tubes is a painful and time-consuming process. Without his disability support personnel, J.M. was also unable to communicate effectively with medical personnel. He was unable to use the call bell when he needed medical attention, and when nurses and doctors were present, he was unable to communicate changes in symptoms, pain, discomfort, and other needs. Frequent rotation of medical personnel also meant that staff were unfamiliar with his baseline, unique symptoms, and how to accommodate his communication and other support needs. J.M. was repeatedly denied access to the disability supports he required – both his mother and his professional support staff – to access medical care. It was only when the nurses experienced four to five days of his high support needs and the threat to his recovery was apparent that the hospital permitted J.M. to access his support personnel.

- P.J. is a 48-year-old woman with Down syndrome and other health conditions. P.J. was hospitalized for COVID-19 for two weeks in April. Due to the hospital's no-visitor policy, which provided clear exceptions for mother/infant, labor and delivery, pediatrics, P.J. was refused access to the disability support personnel (her staff from her group home and family members) necessary for her to communicate effectively, including to understand proposed treatment options, make informed decisions, and provide informed consent. P.J. was also refused video access to her family and support staff. Her mother said nothing had ever devastated her so much in her lifetime. While P.J. eventually recovered from COVID-19 and was released from the hospital, she was denied her right to meaningfully and effectively participate and communicate regarding her symptoms and health care treatment options while hospitalized.

- T.F.¹ lives with intellectual disabilities near Petersburg, Virginia. On June 8, he called 911 and was transported by ambulance to an emergency care facility near his home for abdominal pains. During his three-hour stay, building staff denied him access to his disability support professional (DSP) who was needed to help him explain his symptoms, understand what medical personnel were telling him, ask questions, and to allow him to provide informed consent for the proposed treatment options. T.F.'s DSP, who rushed to the health care facility during his off-hours after hearing he had called 911, was prevented from entering the building and told he had to remain in his car, which he did for the entire time T.F. was being treated. As T.F. was being prepared to be discharged and the nurse explained the results of the tests they had performed, T.F. again requested that his DSP be present to help him understand the information. T.F. reported that the nurse promised to share the information with his DSP at the exit, but she did not. Interestingly, the facility's no-visitor policy states that "exceptions will be considered based on end-of-life situations or when a visitor is essential for the patient's emotional well-being and care." Even though the presence of T.F.'s support person was essential for his emotional well-being and care, and both T.F. and his DSP made separate requests to the facility to accommodate T.F.'s disability needs, the facility denied T.F. this reasonable accommodation. T.F. feels like he was unable to understand and communicate with medical personnel while he was present. T.F. said he felt his treatment at this facility was "not right" and "not fair."

People with disabilities are already at higher risk of contracting COVID-19 and experiencing life-threatening complications from the coronavirus. Many others with disabilities may need to be admitted to the hospital for other reasons. It is critical that, in any event, they be able to effectively communicate with medical personnel and receive any other needed disability-related accommodations during this pandemic.

We urge you to immediately take swift action and issue a state level policy that comports with federal law.

On June 9, 2020, the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services held a national press conference to [announce](#) the favorable and precedent-setting resolution of a complaint filed against the State of Connecticut for its lack of a clear and lawful hospital visitation policy addressing the rights of patients with disabilities. Connecticut's revised statewide policy, issued by executive order and emergency regulation, can be accessed [here](#). With this resolution, OCR made clear its expectations for how states and hospitals nationwide

¹ T.F. is using fictitious initials in order to protect his privacy.

can simultaneously safeguard public health and adhere to legal and ethical obligations. Some of the signatories on today's letter were involved in filing the Connecticut complaint.

On May 15, 2020, six national disability rights groups published an [Evaluation Framework](#) document to assist stakeholders in determining whether state and hospital no-visitor policies unfairly discriminate against patients with disabilities. The document lists some of the critical elements found in non-discriminatory visitor policies and includes links to and language from some of the better state policies.

We urge you to use this Framework to develop and issue a state level policy that provides clear expectations for all hospitals in Virginia. Specifically, we encourage you to adopt a policy that includes the following elements:

- The state policy should be mandatory and directly apply to facilities, rather than directing the facilities to take a separate action to revise their own policies by a certain date.
- The state policy must make clear that disability support persons are allowed for patients with any kind of disability who need them, including patients with physical, communication, mental health, cognitive, and developmental disabilities.
- The state policy must make clear that patients with disabilities – regardless of their COVID-19 status – are entitled to access in-person disability support persons.
- The state policy should acknowledge that the 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 state policy should clarify that designated support persons may be a family member, personal care assistant, similar disability service provider, or other individual knowledgeable about the management of their care, to physically or emotionally assist them or to ensure effective communication during their stay in the facility, provided proper precautions are taken to contain the spread of infection.
- The state policy should clarify that patients may designate more than one support person, even if the facility determines for safety reasons to allow only one to be present at a time.
- The state policy should clarify that support persons should be allowed to reasonably leave and re-enter the facility as long as safety mitigation measures are undertaken.
- The state policy should clarify that support persons should be permitted to safely eat, drink, and use the restroom while present in the hospital, as long as safety mitigation measures are undertaken.
- The state policy should encourage facilities to provide appropriate Personal Protective Equipment (PPE) to be worn by designated support persons as instructed by the facility for the duration of the visit. If the facility does not have PPE for the support person, PPE supplied by the support person that the facility finds adequate may be used.

- The state policy should require facilities to clearly advertise and post notice of the policy 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.
- The state policy should be available in different languages and formats to ensure access to individuals who do not speak English and those individuals with vision impairments.
- The state policy must remind facilities of their continuing legal obligation to ensure effective communication regardless of the presence of a support person, which may require the use of qualified interpreters or assistive technology.
- The state policy should include a contact person to which questions or violations of the policy may be addressed.

We greatly appreciate your efforts during the pandemic to keep Virginians healthy. We ask that the support needs and civil rights of individuals with disabilities be addressed with a comprehensive policy on required accommodations and exceptions to hospital no-visitor policies. Please do not hesitate to contact **Tonya Milling**, Executive Director of The Arc of Virginia, at Tel: 804-649-8481 (ext. 101) or tmilling@thearcofva.org if you have questions regarding this matter or would like additional information. Thank you for your attention to this matter.

Respectfully,

A Life Like Yours Self-Advocacy Alliance
 Appalachian Independence Center
 Arlington Inclusion Task Force
 Autism Society Central Virginia
 Autistic Self Advocacy Network
 Blue Ridge Independent Living Center
 Brain Injury Association of Virginia
 Center for Public Representation
 CommunicationFIRST
 disAbility Law Center of Virginia
 Disability Rights and Resource Center
 Down Syndrome Association of Northern Virginia
 Eastern Shore Center for Independent Living, INC
 Independence Center, Inc.
 Independence Empowerment Center

Independence Resource Center, Inc.
Junction Center for Independent Living, Inc.
Lynchburg Area Center for Independent Living Inc
Resources for Independent Living Inc
The Arc of Augusta
The Arc of Central Virginia
The Arc of Greater Prince William
The Arc of Harrisonburg and Rockingham
The Arc of Lenowisco
The Arc of Loudoun County
The Arc of New River Valley
The Arc of North Central Virginia
The Arc of Northern Shenandoah Valley
The Arc of Northern Virginia
The Arc of the Piedmont
The Arc of Southern Virginia
The Arc of Southside
The Arc of Virginia
The Arc of Warren County
The Arc of Williamsburg
The Disability Resource Center of the Rappahannock Area, Inc
The Partnership for People with Disabilities at VCU
Valley Associates for Independent Living
Virginia Association of Centers for Independent Living
Virginia Association of Community Rehabilitation Programs
Virginia Board for People with Disabilities