



EVALUATION FRAMEWORK FOR HOSPITAL VISITOR POLICIES

Issued: May 15, 2020

A big barrier facing patients with disabilities during the COVID-19 pandemic is strict no-visitor policies that hospitals and other health care facilities across the country have enacted to contain the spread of the virus. These policies frequently discriminate against people with disabilities who require support from family members or staff to effectively communicate with medical personnel or to otherwise receive equal access to treatment. This guidance document lays out the legal framework for required reasonable modifications to state and hospital no-visitor policies and identifies a number of criteria that stakeholders can use to evaluate such policies in order to ensure that they comply with federal disability rights laws.

Legal Framework

For many with disabilities, having a family member or support person with them while receiving medical care is critical to ensuring effective communication between the patient and treating medical personnel, and to helping the patient with orientation, emotional self-regulation, medical decision-making, and personal care. Communication is essential to medical care. The patient must have a way to explain and alert medical personnel to their changing symptoms and daily care needs, and doctors and other medical professionals must ensure the patient understands and agrees with the proposed treatment plan. Doctors have an ethical obligation to seek and obtain informed consent from every patient, something that cannot take place if the patient does not have the tools and supports necessary to become informed, ask questions, make decisions, and communicate consent. No-visitor policies pose serious barriers to individuals with disabilities who require in-person supports. These include, but are not limited to, people who are deaf, blind, and deafblind, who cannot rely on speech to communicate, who have mobility impairments, and people with psychosocial, intellectual, developmental, or cognitive disabilities who rely on in-person supports for orientation, emotional support and anxiety management, and assistance with making decisions.

The Americans with Disabilities Act,¹ Section 504 of the Rehabilitation Act,² and Section 1557 of the Affordable Care Act³ each protect patients with disabilities and entitle them to reasonable modifications and accommodations to ensure equal access to treatment. As the U.S. Department of Health and Human Services, Office for Civil Rights has stated, these laws remain in effect during the current crisis and states and hospitals must take steps to ensure people with disabilities are able to access and benefit from medical treatment, including by providing effective communication, meaningful access to information, and reasonable modifications to address the unique needs of individuals with disabilities.⁴

When a family member or other support person is prohibited from being in the hospital, the patient with a disability is unlawfully denied equal access to medical treatment, including by being denied effective communication. Without reasonable modifications to visitor policies, patients with disabilities can experience serious, adverse outcomes, including: (1) being deprived of their right to make and communicate informed consent; (2) being subjected to the unnecessary use of physical and chemical restraints; (3) being denied adequate and necessary medical treatment and care; and (4) experiencing substantial and lasting emotional harm. A support person can help some disabled patients express and address their basic physical needs that are not visually apparent to someone who does not know them (*e.g.*, discomfort, hunger, thirst, pain), changes in their symptoms, or needs related to a history of trauma, and to ask questions. When these patients are denied access to a support person, they are at substantial risk of receiving substandard medical care and having poorer health outcomes than patients without disabilities.

It is critical that all reasonable steps be taken to ensure support persons such as family members, direct support professionals, guardians and health care agents are permitted in-person access to the patients with a disability who need them. The Consortium for Citizens with Disabilities and the American Academy of Developmental Medicine and Dentistry have both issued documents⁵ outlining the critical importance of such modifications to no-visitor policies.

¹ 42 U.S.C. §§ 12131-12134, 12181-12189; 28 C.F.R. §§ 35.130, 35.160, 36.302 and 36.303; *see also* DOJ, Emergency Management Under Title II of the Americans with Disabilities Act at I (July 26, 2007), available at <https://www.ada.gov/pcatoolkit/chap7emergencymgmt.htm>.

² 29 U.S.C. § 794; 45 C.F.R. §§ 84.4 and 84.52; 28 C.F.R. § 41.51.

³ 42 U.S.C. § 18116; 45 C.F.R. §§ 92.101(a) and 92.101(b)(2)(i); 45 C.F.R. § 92.205.

⁴ U.S. Department of Health and Human Services, Office for Civil Rights, “Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease (COVID-19),” Mar. 28, 2020, available at: https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf?fbclid=IwAR351WokrC2uOLIPxDR0eiAizAO8OXwhBt0asYiXi9_1XW4rnAKW8kxcog

⁵ Consortium for Citizens with Disabilities, Letter to Hospital Administrators, April 29, 2020, available at: <http://www.c-c-d.org/fichiers/Sign-on-letter-supporters-in-hospitals-hospital-admins.pdf>; Consortium for Citizens with Disabilities, Letter to Governors, April 29, 2020, available at: <http://www.c-c-d.org/fichiers/Sign-on-letter-supporters-in-hospitals-governor.pdf>; American Academy of Developmental Medicine and Dentistry, Hospitalized Patients & Designated Support Staff Policy Statement Committee on Public Policy and Advocacy, April 2020, available at: <https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5e9e1cbefc832d0a6866fed4/1587420352080/Visitation-PolicyStatement.pdf>

Disability-related communication supports may include access to interpreters, specialized assistive technology, written materials in accessible formats, or the presence of a family member, personal care assistant, or trained disability service provider if that is what the patient with a disability requires to communicate effectively and otherwise benefit from medical treatment. Support persons can also provide critically important physical and emotional support necessary for the patient to receive equal access to the treatment and other services the hospital provides to people without disabilities. People who rely on Medicaid-funded Home and Community-Based Services (HCBS) to assist with activities of daily living also may need support from their Direct Service Professionals (DSPs) to facilitate access to treatment during a short-term hospital stay. Indeed, the Coronavirus Aid, Relief, and Economic Security (CARES) Act recently passed by Congress includes provisions to facilitate the presence of DSPs during acute hospitalizations.⁶

Although safety concerns are critical, the Centers for Disease Control and Prevention has published guidelines on how to safely accommodate “essential visitors,” recognizing the necessity of support persons for certain patients.⁷ Numerous states have already modified no-visitor policies to ensure that individuals with disabilities have access to necessary in-person supports while hospitalized⁸ and others already make exceptions in other circumstances (such as when patients are minors, in labor, or at the end of life). These supports are not only required by federal disability rights laws, but they may save lives by ensuring equal access to healthcare, enhancing the safety of individuals with disabilities seeking hospital or clinic-based care, and increasing the effectiveness and efficiency of health care staff.

Evaluation Criteria

The following questions and criteria can help stakeholders evaluate whether state or hospital no-visitor policies are compliant with federal disability rights laws. In the footnote to each criterion are examples of state policies that address the relevant modification. Although each of these policies has weaknesses, and this document does not endorse any of them in their entirety, the examples may be helpful as an evaluation tool when reviewing other state or hospital no-visitor policies.

⁶ Pub. L. 116-136 sec. 4411 (2020), Section 3715, available at <https://www.congress.gov/116/bills/hr748/BILLS-116hr748enr.pdf>.

⁷ Centers for Disease Control and Prevention, “Interim Infection Prevention and Control Recommendations for Patients with Suspected or Confirmed Coronavirus Disease 2019 (COVID-19) in Healthcare Settings,” April 13, 2020, available at: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/infection-control-recommendations.html> (acknowledging that the presence of a support person can be “essential for the patient’s physical or emotional well-being and care”).

⁸ See, e.g., New York Department of Health, “Health Advisory: COVID-19 Updated Guidance for Hospital Operators Regarding Visitation,” April 10, 2020, available at: https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf.

1. **Hospital is required to follow the policy:** Does the state policy directly require (rather than merely encourage) hospitals to allow disability support persons in the room with the patient or require hospitals to adopt disability-related exceptions to their no-visitor policies?⁹
2. **Policy covers hospital and non-hospital facilities:** Does the policy address hospitals, non-hospital facilities (*e.g.*, long-term care, skilled nursing, and post-acute facilities), ambulances, and medical offices, as well as all patient areas within the facility (*e.g.*, ER, ICU, dialysis, in-patient, out-patient) where the person with a disability may require support?¹⁰
3. **Policy covers all disabilities:** Does the policy address patients with *any* type of disability who may require support personnel? If specific examples of disabilities are listed, does the policy include communication, mental health, and physical disabilities, and not just I/DD or dementia?¹¹
4. **Policy requires effective communication:** Does the policy provide for effective communication supports at all times, including requiring facility staff to regularly assess and document the patient’s communication needs throughout the patient’s stay in the hospital?¹²
5. **Policy recognizes a support person as different than a visitor:** Does the policy clarify that support persons are not “visitors” and are required by law because they are essential to

⁹ Examples:

- [New York](#): provides that “hospitals are required to permit a patient support person at the patient bedside” for patients with disabilities, pediatric patients, and labor and delivery patients.
- [New Jersey](#): provides that “hospitals are required to allow a designated support person to be with the disabled patient during hospitalization.”
- [Maryland](#): requires all licensed hospitals in the state to revise their no-visitor policies by a certain date to include disability-related exceptions and other provisions.

¹⁰ Examples:

- [Alabama](#): applies to “all hospitals and nursing home/long term care facilities (including assisted living and specialty care assisted living facilities).”
- [North Carolina](#): makes clear that individuals with disabilities “may need to have a caregiver accompany them in either the ambulance or in the hospital.”
- [California](#): applies to all health care facilities, including skilled nursing facilities.

¹¹ Examples:

- [Oregon](#): broadly addresses “patients who need assistance due to their disability if in-person visitation is necessary to facilitate treatment [or] ensure the safety of the patient or facility staff.”
- [Maryland](#): discusses “individuals with disabilities,” without listing disability types.

¹² Examples:

- [HHS-OCR Bulletin](#): reiterates obligations under federal civil rights laws to “provid[e] effective communication with individuals who are deaf, hard of hearing, blind, have low vision, or have speech disabilities through the use of qualified interpreters, picture boards, and other means.”
- [Illinois](#): describes “the use of effective communication” as “critical to a patient’s autonomy and ability to participate in their care.”

patient care, communication, and autonomy and necessary to ensure equal access to treatment?¹³

6. **Policy allows more than one support person:** Does the policy allow the patient to have more than one support person, even if only one support person can be present at a time?¹⁴
7. **Policy does not prevent access to support person who has had previous direct contact with COVID-19 patient but is asymptomatic:** Does the policy allow access for an asymptomatic support person who has previously had direct contact with a COVID-19 patient as long as the support person takes additional appropriate precautions to contain the spread of the virus?¹⁵
8. **Policy allows the support person access to restroom, food and drink:** Does the policy allow a support person to eat, drink, and use the restroom while they are in the hospital?¹⁶

¹³ Examples:

- [California](#): characterizes disability support persons as “medically necessary” and “essential to patients with physical, intellectual, and/or developmental disabilities and patients with cognitive impairments.”
- [Illinois](#): describes “the presence of an assistant, aide, or family member” as a reasonable accommodation or modification.
- [New York](#): distinguishes visitors from “patient support persons.”
- [Maryland](#): uses the term “support persons,” and the title of its policy is “Access to Support for Persons with Disabilities in Hospital Settings.”

¹⁴ Examples:

- [California](#): allows two support people to be designated for hospitalized patients, although only one may be present at a time.
- [New Jersey](#): provides that “if the hospital determines that a second support person is necessary for the disabled patient, and PPE availability permits, hospitals are permitted to have a second designated support person and may permit either designated support person to be present with the disabled patient.”
- [New York](#): allows patients with disabilities to “designate two support people; but only one support person may be present at a time.”
- [Maryland](#): does not limit the number of support people allowed.

¹⁵ Examples:

- [New York](#): states that support people who have had close contact with and prior exposure to a COVID-19 patient should “wear a surgical or procedure mask throughout their time in the hospital; practice scrupulous hand hygiene; remain in the patient’s room except for entrance and exit from the hospital; and while in the room, a gown and gloves should be worn to prevent the person’s hands or clothes from becoming contaminated. Eye protection should be worn while in the room if available.”
- [Maryland](#): Apart from “persons with COVID-19 symptoms,” Maryland’s policy places no limitations on who can be a disability support person.

¹⁶ Examples:

- [Oregon](#): states that “private visiting areas may be offered to patients with roommates or other privacy concerns if these rooms can be cleaned appropriately between essential individuals’ visits.” It also states that “before entering a patient room and after leaving a patient room, essential individuals shall wash hands with soap and water for 20 seconds, or clean hands with alcohol-based hand sanitizer.”
- [Maryland](#): has no restrictions on support personnel ability to eat, drink, or use the restroom while in the hospital.

9. **Policy addresses PPE:** Does the policy address how personal protective equipment (PPE) for support persons should be handled and direct the hospital to provide PPE for a support person who does not have it?¹⁷
10. **State and hospital policies are available to general public:** Are both the state’s policy and each individual hospital’s policy publicized to the general public, and easily found on the state’s or hospital’s main COVID-19 website?¹⁸
11. **Policy provides a contact person to address questions or violations:** Does the policy provide contact information for questions and concerns that may arise for the patient and support persons and require that hospitals appoint a contact person or disability ombudsperson?¹⁹
12. **Is the policy document available in different formats and languages?** Does the policy include options to obtain the policy in other languages, large print, braille, or another format?²⁰

For more information, please contact:

Alison Barkoff, Center for Public Representation, abarkoff@cpr-us.org
Samantha Crane, Autistic Self Advocacy Network, scrane@autisticadvocacy.org
Tauna Szymanski, CommunicationFIRST, tszymanski@communicationfirst.org
Shira Wakschlag, The Arc, wakschlag@thearc.org

¹⁷ Examples:

- [New Jersey](#): states that PPE “should be given to and worn by the designated support person.”
- [Oregon](#): provides that “support persons must comply with any health facility instructions on personal protective equipment.”
- [Maryland](#): states that “all support persons shall be required to don appropriate PPE and comply with hospital policies regarding use and conservation of that PPE.”

¹⁸ Example:

- [New York](#): requires hospitals to “post signage notifying the public of the suspension of visitation in all hospital entrances and in parking lots. In addition, these policies should be posted to the hospital’s website and social media pages.”

¹⁹ Example:

- [New Jersey](#): provides the name and email address of the Executive Director of the state’s Certificate of Need and Healthcare Facility Licensure program for questions.

²⁰ Example:

- [Oregon](#): provides contact information for an individual to “get this document free of charge in other languages, large print, braille or a format you prefer.”