











EVALUATION FRAMEWORK FOR HOSPITAL VISITOR POLICIES

A big barrier facing patients with disabilities during the COVID-19 pandemic is strict novisitor policies that hospitals and other health care facilities across the country have enacted to help 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 under disability rights laws for reasonable accommodations to state and hospital no-visitor policies and lists criteria stakeholders can use to evaluate such policies to ensure they comply with federal disability rights laws.

On June 9, 2020, the Office for Civil Rights (OCR) at the U.S. Department of Health and Human Services <u>announced</u> it had resolved complaints filed on May 4 and May 12, 2020, by several disability rights organizations against the State of Connecticut and Hartford Hospital alleging their no-visitor policies discriminated against patients with disabilities. With these resolutions, and the resulting <u>new Connecticut policy</u>, OCR has made clear its expectations for how states and hospitals nationwide can both safeguard public health and adhere to their legal and ethical obligations.

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 Act ³ each protect patients with disabilities and entitle them to reasonable modifications and accommodations to ensure equal access to treatment. As OCR emphasized early in the pandemic, these laws remain in effect during the 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 necessary 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 no-visitor policies, patients with disabilities can experience serious, adverse outcomes. These include being deprived of their right to make and communicate informed consent; being subjected to the unnecessary use of physical and chemical restraints; being denied adequate and necessary medical treatment and care; or experiencing discrimination or neglect. These types of injuries can cause substantial and lasting emotional harm.

A support person can help some disabled patients express and address 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

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), 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), 92.101(b)(2)(i) and 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)," March 28, 2020, https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf.

and the American Academy of Developmental Medicine and Dentistry have both issued documents⁵ outlining the importance of such modifications to no-visitor policies.

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

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 Even before OCR's announcement on June 9, 2020, numerous states had already modified no-visitor policies to ensure that individuals with disabilities have access to necessary in-person supports while hospitalized.⁸ 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.

⁵ Consortium for Citizens with Disabilities, Letter to Hospital Administrators, April 29, 2020, 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, 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, https://static1.squarespace.com/static/5cf7d27396d7760001307a44/t/5e9e1cbefc832d0a6866fed4/1587420352080/Visitation-PolicyStatement.pdf

⁶ Pub. L. 116-136, sec. 4411 (2020), Section 3715, 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," last updated May 18, 2020, https://www.cdc.gov/coronavirus/2019-ncov/hcp/infection-control-recommendations.html (acknowledging 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,

https://opwdd.ny.gov/system/files/documents/2020/04/doh_covid19_hospitalvisitation_4.10.20.pdf.

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. The footnote to each criterion lists examples of state policies that address the relevant modification. Although each of these state policies has its 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.

- 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? Alternatively, does it require (rather than simply encourage) 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, inpatient, 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 all communication, mental health, and physical disabilities, or is it limited to a very few disabilities like intellectual and developmental disabilities or dementia?¹¹

• <u>Connecticut</u>: policy adopted by emergency regulation, requiring facilities to allow patient access to necessary disability support persons.

• 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.

- <u>Alabama</u>: applies to "all hospitals and nursing home/long term care facilities (including assisted living and specialty care assisted living facilities)."
- <u>California</u>: applies to all health care facilities, including skilled nursing facilities.
- Connecticut: applies to all hospitals as well as outpatient clinics, dialysis units, and surgical facilities.
- <u>Illinois</u>: applies to all "health care facilities (including hospitals)," including emergency rooms and other areas of hospital.
- North Carolina: makes clear individuals with disabilities "may need to have a caregiver accompany them in either the ambulance or in the hospital."
- Rhode Island: applies to all health care facilities.

⁹ Examples of mandatory policies:

[•] New Jersey: provides that "hospitals are required to allow a designated support person to be with the disabled patient during hospitalization."

¹⁰ Examples of policies applying broadly to different facilities:

¹¹ Examples of policies covering patients with any kind of disability:

- 4. **Policy requires effective communication:** Does the policy provide and emphasize the need for effective communication supports at all times? Does it require 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 their presence is permitted by law because they are essential to patient care, communication, and autonomy and necessary to ensure equal access to treatment?¹³
- <u>Connecticut</u>: addresses patients "with disabilities that may include, but not be limited to, altered mental status, physical, intellectual or cognitive disability, communication barriers or behavioral concerns, who need assistance due to the specifics of their disability."
- Maryland: discusses "individuals with disabilities," without listing disability types.
- 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."
- ¹² Examples of policies specifically addressing need for communication supports:
 - <u>HHS-OCR Bulletin</u>: 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."
 - <u>Connecticut</u>: emphasizes continuing facility "obligations to provide patients with effective communication supports or other required services, regardless of the presence of a designated support person or other reasonable accommodation, consistent with" federal and state law.
 - Illinois: describes "the use of effective communication" as "critical to a patient's autonomy and ability to participate in their care," to avoid the risk of medical providers "substituting misplaced assumptions and potential biases about the person with a disability for verifiable information and medical history," and to maximize "transparency in process and protocols, which helps to ensure that the medical provider and the person with a disability understand each other and agree." It further observes that support persons may be necessary to "facilitate communication between the individual and hospital personnel; ascertain the individual's pertinent medical history; secure from the individual 'informed consent' for treatment; [and] ensure the individual's participation in care planning."
 - Rhode Island: states that in addition to support persons, "patients with a disability shall similarly be allowed to use assistive technology (e.g., smart phones, tablets, and other communication devices, such as assistive technology and communication boards, to facilitate communication and ensure equal access."
- ¹³ Examples of policies distinguishing between visitors and support persons:
 - <u>California:</u> characterizes support persons as "medically necessary" and "essential to patients with physical, intellectual, and/or developmental disabilities and patients with cognitive impairments."
 - Connecticut: recognizes that blanket no-visitor policies create "barriers to obtaining the care [patients with disabilities] require as well as inconvenience and distress" and that support persons are "knowledgeable about the management of [the patient's] care, to physically or emotionally assist them or to ensure effective communication during their stay."
 - <u>Delaware</u>: state public health division "does not consider support persons for individuals with intellectual or developmental disabilities to be visitors"; describes support persons as "essential to the care of the patient (medically necessary)."

- 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
- <u>Illinois</u>: describes "the presence of an assistant, aide, or family member" as a reasonable accommodation or modification.
- Maryland: uses the term "support persons," and the title of its policy is "Access to Support for Persons with Disabilities in Hospital Settings."
- New York: distinguishes visitors from "patient support persons."
- Rhode Island: recognizes that support persons may be essential to a disabled patient's care, and may "facilitate communication with hospital staff, accessibility, equal access to treatment and/or the provision of informed consent in accordance with the civil rights of patients with disabilities."
- ¹⁴ Examples of policies permitting designation of more than one support person:
 - <u>California:</u> allows two support people to be designated for hospitalized patients, although only one may be present at a time.
 - <u>Connecticut</u>: patient who is hospitalized for more than one day "may designate two support people, provided only one support person may be present at a time."
 - <u>Delaware</u>: allows patients with intellectual and/or developmental disabilities to designate two support people, although only one may be present at a time.
 - <u>Illinois</u>: health care facilities should allow "at least one" support person to be present in emergency room and "to accompany those admitted to the hospital" and to allow hospitalized patients to designated two support people, with only one being allowed to be present at any given time.
 - New Jersey: provides that "especially with prolonged hospitalizations, the patient or family/caregiver may designate two support people; but only one support person may be present at a time."
 - New York: allows patients with disabilities to "designate two support people; but only one support person may be present at a time."
 - Rhode Island: allows two support people to be designated in some cases, "to ease the burden on any one individual support person," although only one may be present at a time.
- ¹⁵ Examples of policies allowing asymptomatic support persons even if they have been exposed to COVID:
 - <u>Connecticut</u>: support persons "must be asymptomatic for, or not have previously been confirmed positive for, COVID-19"; any support persons "suspected of having been exposed to COVID-19 may be denied access where attendant risks of such access cannot be reasonably mitigated."
 - <u>Delaware</u>: allows any type of support person but recommends excluding those with "confirmed or suspected COVID-19" and those who "present[] with or develop[] symptoms of COVID-19."
 - <u>Illinois</u>: states that "support persons should be screened for illness daily upon entry to the facility with a temperature check and symptom checklist."
 - New Jersey: requires the support person to be "asymptomatic for COVID-19 and must not be a suspect or recently confirmed case."

- 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
- 9. **Policy addresses PPE:** Does the policy address how personal protective equipment (PPE) for support persons should be handled? Does it 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:** Is the state policy posted on the state's main COVID-19 website? Does the state policy direct each individual hospital to publicize its policy to the general public, including on its 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
- New York: recommends excluding support people with "confirmed or suspected COVID-19" and those who "present with or develop symptoms of COVID-19, but "allows support persons who have "been a close contact" of a COVID-19 patient but lists additional measures they should take to mitigate the risk of transmission.

¹⁶ Examples of policies accommodating support person daily needs, either inside or outside the hospital:

- Connecticut: allows support persons to leave the facility as long as they are re-screened on re-entry.
- Maryland: has no restrictions on support personnel ability to safely eat, drink, or use the restroom outside a COVID-positive patient's room while in the hospital.
- <u>New Jersey</u>: contemplates support persons leaving and re-entering the hospital as long as they are re-screened for COVID symptoms.
- 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."

¹⁷ Examples of policies addressing PPE:

- <u>Connecticut</u>: states that "the Facility shall provide appropriate Personal Protective Equipment (PPE) to be worn by the designated support person as instructed by the Facility for the duration of the visit."
- <u>Illinois</u>: states that support persons must "comply with any instructions on personal protective equipment (PPE), also to be provided by the facility."
- New Jersey: states that PPE "should be given to and worn by the designated support person."
- ¹⁸ Examples of policies addressing notice:
 - <u>Connecticut</u>: states that "notice of the Facility's support person policy including the requirements contained herein shall be posted at patient entry points in the Facility on the Facility's website and be provided to the patient at time services are scheduled or initiated."
 - 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."
 - Oregon: requires facilities to provide "appropriate signage regarding visitation and screening protocols and provide this information to staff, patients and essential individuals."

support persons and require that hospitals appoint a contact person or disability ombudsperson?¹⁹

12. **Policy document is 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

¹⁹ Examples of policies including or addressing need for contact information for questions:

[•] 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.

Rhode Island: provides phone numbers to direct clinical and non-clinical questions about the policy.

²⁰ Examples of policies addressing need for information in different formats and languages:

[•] 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."