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Hospital No-Visitor Policies Endanger People With Disabilities, Advocates Say

by Michelle Diamant | May 8, 2020

No visitor sign



A temporary "No Hospital Visitors" sign was posted at the Mayo Clinic entrance in Jacksonville, Fla. because of concerns about the coronavirus. (Will Dickey/Florida Times-Union/TNS)

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Disability advocates are alarmed that no-visitor policies are forcing people with developmental disabilities — including those who are nonverbal — to go it alone at hospitals across the nation.

Hospitals are sharply limiting access to their facilities in an effort to slow the spread of COVID-19. And in many cases, there are no policies in place to ensure an exception for individuals with disabilities who require assistance.

“We are aware of only seven states or state hospital associations that have issued statewide guidance or policies that explicitly make clear that people with disabilities have the right to be accompanied by a disability support person if that is necessary for them to communicate effectively or to otherwise ensure they are able to adequately access and benefit from the medical treatment that is offered to patients without underlying/preexisting disabilities,” said Tauna Szymanski, executive director and legal director at CommunicationFIRST, a national advocacy group focused on communication disabilities.

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Szymanski's group along with Disability Rights Connecticut, the Center for Public Representation and The Arc filed a [complaint](#) this week with the U.S. Department of Health and Human Services' Office for Civil Rights alleging that recent guidance from the state of Connecticut violates the Americans with Disabilities Act and other laws. The recently-issued state guidance said that a support person should be allowed to accompany people with intellectual and developmental disabilities who receive services from the state's Department of Developmental Services, but did not extend the same accommodation to others with similar needs who are not supported by the state agency.

The complaint details the experience of Shane Sessa, 48, who has intellectual disability, cerebral palsy and communication challenges. His mother, who is his legal guardian, was not permitted to accompany him during a three-week hospitalization in April leading Sessa to be confused and afraid and "almost combative," the complaint said. He remains "upset and shaken" and now makes ambulance sounds to show that he is worried about being taken back to the hospital.

The Connecticut complaint is the first to be filed with HHS' Office for Civil Rights since the coronavirus pandemic began related to hospital visitor policies, advocates said. It is one of several efforts underway to ensure accommodations for those with disabilities who require hospitalization for COVID-19 or otherwise.

The American Academy of Developmental Medicine & Dentistry, which represents physicians and other health professionals who treat people with intellectual and developmental disabilities, has warned that barring support people for individuals in this population could lead to detrimental outcomes and is pushing all states to implement visitation policies that allow for a support person. An online [petition](#) the medical group spearheaded has more than 37,000 signatures.

"Regrettably, the 'No Visitors' policies may result in deleterious and sub-optimal clinical outcomes because vital bio-psycho-social information is not available to medical staff. Agency personnel and family caregivers who have this type of information can provide it stat when on site in the patient's room or floor," reads a [policy statement](#) from the group. "Such designated support personnel are not passive 'visitors,' they can provide vital information that can impact clinical decisions and outcomes."

Meanwhile, the Consortium for Citizens with Disabilities, a coalition representing dozens of disability advocacy groups, has crafted letters signed by more than 100 local and national groups that advocates across the country can use to lobby their [governors](#) and [hospital administrators](#).

"In light of the accommodations health providers are already making for classes of patients such as minors, people in labor and people at the end of life, making an additional limited exception to the visitor policy for individuals with disabilities would be a reasonable modification," state the letters, which cite New York, Oregon and Illinois as examples of states that have already issued guidance allowing for such accommodations.

Additionally, the National Down Syndrome Society has put together a [document](#) advising families on what to do if a hospital is denying visitors for a patient with the chromosomal disorder.

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