



Disability Rights Connecticut

"Connecticut's protection and advocacy system"

846 Wethersfield Avenue
Hartford, CT 06114

Sent Via Electronic Mail & U.S. Mail

May 12, 2020

Roger Severino
Director, Office for Civil Rights
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington DC 20201

RE: Emergency Addendum to May 4, 2020 Complaint Regarding Connecticut Guidance on Hospital Visitation Policies: Unlawful Continuing Discrimination at Hartford Hospital

Dear Mr. Severino:

On May 4, 2020, Disability Rights Connecticut (DRCT), Center for Public Representation, Arc of the United States, and CommunicationFIRST submitted a complaint to the Office for Civil Rights (OCR) on behalf of themselves and other disability organizations, asserting that Connecticut's guidance on hospital visitation policies during the COVID-19 public health emergency violated Title II of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act (RA), and Section 1557 of the Patient Protection and Affordable Care Act (ACA). We eagerly await resolution of the issues raised in that complaint.

We incorporate by reference the May 4 Complaint and submit this addendum to alert you that Hartford Hospital – where "Patient G.S.,"¹ described in our May 4 complaint, remains hospitalized – continues to violate Patient G.S.'s civil rights by: (1) refusing to modify its "no visitor" policy and denying access to the disability-related support persons she needs to access and have equal opportunity to benefit from the medical treatment and other services provided to patients without disabilities; and (2) denying her access to effective communication.

As a private hospital and recipient of federal financial assistance, Hartford Hospital's actions violate Title III of the ADA, 42 U.S.C. §§ 12181 *et seq.*; 28 C.F.R. § 36.302 (disability-related modifications required); 28 C.F.R. § 36.303 (communication supports required), Section 504 of the RA, 29 U.S.C. § 794; 45 C.F.R. § 84.4 (prohibition on disability discrimination), 45 C.F.R. § 84.52 (health care facilities

¹ Because Patient G.S. remains hospitalized and is fearful the allegations raised herein will result in negative repercussions for herself and family, we continue to use these fictitious initials. Personally identifiable information can be provided under seal if required.

required to provide communication supports); 28 C.F.R. § 41.51 (requirement to provide aids, benefits, and services to people with disabilities at a level affords equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement as that provided to others), and Section 1557 of the ACA, 42 U.S.C. § 18116; 45 C.F.R. § 92.101(a)(1); 45 C.F.R. § 92.205 (disability discrimination in certain health programs or activities prohibited; covered entities required to ensure programs, services, activities and facilities are accessible).

Despite frequent requests and advocacy by Patient G.S.'s family, DRCT, and CommunicationFIRST since Patient G.S. was admitted on April 19, 2020, and despite having been informed of the May 4 Complaint, Hartford Hospital has refused to modify its discriminatory no-visitor policy for over three weeks. In fact, hospital personnel have informed us that Hartford Hospital will not do so until it receives new guidance from the State of Connecticut requiring it to do so. Hartford Hospital's actions and inactions are negatively impacting Patient G.S.'s health and well-being. Every day that goes by without effective communication and access to disability support persons causes additional harm to Patient G.S.

Since we filed the May 4 Complaint, Patient G.S. has experienced the following:

1. Once entering the ICU at Hartford Hospital on April 30, 2020, G.S. has received fewer services than before to facilitate communications with her health care providers. The hospital agreed to provide two iPad calls per day and one call daily with the attending physician. No sitter was provided and family members were not permitted access to G.S. Over the next few days, access to G.S. consisted of iPad calls lasting on average ten (10) minutes long. Twice hospital staff forgot to call during scheduled iPad times. On some occasions, staff provided updates on G.S.'s status prior to the call enabling family members to convey medical information to G.S. during the call. Other times, staff set up the iPad on a tripod and did not respond to any questions or communications from family members throughout the call.
2. On May 4, DRCT communicated again with counsel from Hartford Hospital clarifying that the family's first choice has always been to be permitted physical access to G.S. DRCT requested again that family members be allowed on the ICU noting that nowhere in Hartford Hospital's protocol is there an exception for the ICU. DRCT corrected the hospital's misconception that the family was requesting access to "visit" G.S. as opposed to providing disability related supports necessary for equal access to medical care and treatment.
3. In the interim, until a family member could be physically present, DRCT requested reinstatement of a sitter immediately to facilitate communication during rounds and consultations by other doctors/specialists. DRCT requested that the sitter be provided with an iPad and allow access to the family so that they could hear and interpret the medical information for the patient. In the event there was not sufficient technology available, the family offered to provide a dedicated iPad for the G.S.'s sole use.
4. In response, counsel for Hartford Hospital replied that because the patient was intubated and sedated, communication was not possible, therefore G.S.'s ability or opportunity to participate in her health care was equal to anyone else without a disability who is also intubated. Additional iPad sessions were also denied so that patient care teams could provide uninterrupted care to all the patients.
5. The family strongly disagreed with the hospital's assertion that G.S. could not communicate and once again attempted to explain the importance of having a support person present to read and

interpret G.S.'s non-verbal cues. In addition, the family reminded the hospital of the importance to provide re-orientation of G.S. repeatedly throughout the day due to her short-term memory deficits. On May 6, *six days after being on the ICU*, staff was instructed on techniques for re-orienting G.S. when staff entered her room. Lastly, family reminded staff how confused and frightened G.S. becomes due to her short-term memory deficits and explained the importance of a support person being there to translate information and emotionally regulate G.S.

6. On May 8, 2020, G.S.'s health had improved to the point where she was beginning to take breaths on her own with the aid of a C-PAP machine and her sedation was at a minimal dose. During iPad sessions, family members could see G.S.'s face was alert and she was focusing better. Given her increased awareness and improving health status DRCT informed Hartford Hospital that G.S.'s communication needs were increasing making it even more imperative that she have a support person with her in the room. DRCT requested that two persons be designated as support persons and that they be allowed access to G.S. for periods of the day, ideally in the morning and late afternoons/evenings. No response was received to this request.
7. Sometime on May 10, 2020, a decision was made to increase sedations again for G.S. The family was told it was because G.S. was becoming feisty and agitated when attempts were made to perform oral hygiene and when, on one occasion, G.S. attempted to reach for the intubation tube with her restrained hand. Family members were not contacted to facilitate communication with G.S. and help her understand before chemical sedations were used. G.S. was administered three different sedatives.
8. On May 11, 2020, a new shift of medical providers began providing care to G.S. After completing an assessment of G.S. the attending physician asked the family to consider Do Not Resuscitate (DNR) measures. The family questioned the basis for such an order and advocated strenuously for continued treatment reminding hospital staff that G.S.'s altered brain metabolism requires more time for her to heal and recover, especially from sedatives. At this time, G.S. remains in the ICU, intubated, sedated, but conscious.

We greatly appreciate your efforts to resolve our complaint against Connecticut. But given the urgency and ongoing nature of the violations of G.S.' civil rights, we urge you to take immediate action to ensure that Hartford Hospital complies with federal disability rights law. We appreciate your prompt consideration of this urgent matter. Please contact Cathy Cushman at 860-990-0715 or Catherine.Cushman@disabilityrightsct.org with any questions.

Respectfully,

Bob Joondeph, Interim Executive
Director
Catherine E. Cushman, Legal Director
Disability Rights Connecticut
846 Wethersfield Avenue
Hartford, CT 06114
Catherine.Cushman@disrightsct.org
860-469-4461 (office)
860-990-0175 (cell)

Alison Barkoff
Director of Advocacy
Center for Public Representation
1825 K Street NW
Washington, DC 20007
abarkoff@cpr-us.org
202-854-1270

Tauna Szymanski
Executive Director & Legal Director
CommunicationFIRST
1629 K Street, NW
Suite 300
Washington, DC 20006
tszymanski@communicationfirst.org
202-556-0573

Shira Wakschlag
Director, Legal Advocacy &
Associate General Counsel
The Arc
1825 K Street, NW
Suite 1200
Washington, DC 20006
Shira@TheArc.org
202-534-3708

Together With:

CommunicationFIRST

CommunicationFIRST is the only national, nonprofit, 501(c)(3) organization dedicated to protecting and advancing the civil rights of the more than five million people of all ages in the United States who, due to disability or other condition, are unable to rely on speech alone to communicate. Run by and for people with expressive communication disabilities, CommunicationFIRST advances its mission by educating and engaging the public, advocating for policy and practice reform, and engaging the justice system to ensure access to effective communication, to end prejudice and discrimination, and to promote equity, justice, inclusion, and opportunity for our historically marginalized community. <https://CommunicationFIRST.org/>

The Arc of Connecticut, Inc.

The Arc Connecticut is our state's oldest and largest advocacy organization for people with intellectual and developmental disabilities (I/DD) and their families. We were founded more than 65 years ago by parents who believed that their loved ones with I/DD should have the supports they needed to live, work, and fully participate in the life of their communities. We are a chapter of The Arc of The United States. The National Arc is the nation's largest organization of and for people with I/DD. In Connecticut, our 13 Arc local chapters deliver over \$100 million in jobs, supports and services to thousands of people in 162 communities. Together, Arcs are the largest provider of supports and services for people with I/DD and their families in Connecticut.

Independence Northwest: Center for Independent Living of Northwest CT, Inc.

IN: Center for Independent Living of Northwest CT, Inc., a federally and state recognized Center for Independent Living, is filing this Complaint on behalf of the people with significant disabilities the organization serves. IN is responsive to our communities and provides systems advocacy to ensure that people with disabilities aren't discriminated against by lack of architectural or attitudinal accessibility and public policy. IN offers peer support, individual advocacy, independent living skills instruction, information and referral, youth transition and transition from nursing facilities to people with all types of disabilities and of all ages.