

## Hospital visitor bans fail disabled patients, complaint says

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**Penny Barsch, of Meriden, stands six feet away from her son, Shane Sessa, in the back yard of the group home where he lives in Portland. When Sessa, who has cerebral palsy, was hospitalized recently for surgery, Barsch was prohibited from accompanying him due to hospital restrictions in place since the onset of the COVID-19 pandemic.**

It's been weeks since Penny Barsch's son was wheeled, screaming, down a hospital corridor while she watched from an iPad, and the memory still haunts her.

Her son Shane Sessa, 48, who is intellectually disabled, needed emergency surgery at Middlesex Hospital. Medical staff had called her on the iPad to get consent for the surgery. But she wasn't allowed to be with Sessa in person because coronavirus has led to hospitals banning visitors.

"Psychologically, it's really done a number on me," said Barsch, of Meriden. "It makes me feel like I broke a promise to my son to be there to protect him. That's what he expects of me. A lot of people don't understand his voice, so he depends on me to be his voice."

She's certain that if the hospital had allowed her in to visit her son last month, she would have been able to calm him before the surgery and would have helped him afterward when he was consumed with fear and needed to be tied down so as not to pull out a tube. He never needed that kind of restraint in the past, she said.

Sessa is one of three people with disabilities named in a complaint filed earlier this month with the Office for Civil Rights in the U.S. Department of Health and Human Services. The complaint argues that Connecticut has failed to ensure that people with disabilities who are hospitalized receive reasonable accommodations during the COVID-19 public health emergency.

The organization that filed the complaint – a non-profit advocacy group, Disability Rights Connecticut – said that people with disabilities are not being permitted “necessary exemptions to strict ‘no visitor’ policies adopted by hospitals due to the pandemic.”

As a result, people with disabilities are being denied equal access to medical treatment, the complaint says, because they are denied “effective communication” and the right to provide “informed consent,” leading to “substantial and lasting emotional harm.” Some people with disabilities have unnecessarily been restrained, the complaint says, either by being tied down or sedated. Had a support person or relative been present to calm the patient, advocates and families say, no restraints would likely have been necessary.

“*People with disabilities retain their rights when they go into a hospital, even during a pandemic.*”

— Catherine Cushman, legal director, Disability Rights Connecticut

“It’s important for people to know that people with disabilities retain their rights when they go into a hospital, even during a pandemic,” said Catherine Cushman, legal director for Disability Rights Connecticut. “And that policies need to be modified in order to accommodate people’s individual needs. That’s really what discrimination law is all about.”

Cushman noted that while advocates are not asking hospitals to “allow lots of people in and create an unsafe environment ... these blanket policies that are sort of one size fits all, they end up doing a lot of harm in preventing people with disabilities from having equal access to medical care.”

The state has provided the Office of Civil Rights with a draft of an order “consistent with its neighboring states that would ensure reasonable and safe access for the disabled and their support persons to the health care facilities at issue,” said Max Reiss, spokesman for Gov. Ned Lamont. However, he said, OCR “has not accepted the State’s proposed terms and instead has requested additional terms not adopted by our neighboring states.”

Reiss did not provide details about OCR’s concerns, but said the state “believes some of the terms OCR is requesting could put at risk the health and safety of those most vulnerable to the COVID-19 disease.”

The state is anxious, he said, “to join its neighboring states by adopting reasonable measures that will further ensure the rights of the disabled are protected but also take into account the health and safety of our most vulnerable patients ... We will continue to work with OCR to achieve that goal as quickly as possible.”

Calls and emails requesting a comment from the federal Office of Civil Rights were not returned.

The State Department of Developmental Disabilities has provided families served by that agency with a form that says their loved one is a client of DDS and requires a support person in the hospital. The department said it worked with the Connecticut Hospital Association to develop the guidance and noted in a statement that the association “will strongly recommend and work with hospitals to allow one support person to accompany an individual served by DDS.”

However, according to the complaint, DDS and the hospital association have no authority over the hospitals, and the guidance leaves out the thousands of intellectually disabled people who are not clients of DDS, as well as thousands of others with different disabilities.

Cushman said advocates are seeking a more far-reaching order that would include patients with a wide range of disabilities who need an accommodation such as a family member, personal care assistant or other support person with them in the hospital. She said that order would need to come from the state

Department of Public Health, which is the agency with authority over the hospitals, or from Gov. Ned Lamont's office as an emergency executive order. The Disability Rights group has been unable to get DPH to move on the issue; that agency was led until recently by Renee Coleman-Mitchell.

In a statement issued April 28, before Coleman-Mitchell stepped down from her role as commissioner, the Disability Rights advocates deemed her "silent" and the department as "a no-show" on the issue.

A spokesman for DPH said he could not comment on the complaint because it is "a pending legal matter."

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— Penny Barsch

For a former patient like Shane Sessa, who lives in a group home in Portland, the trauma of his hospital experience continues.

His mother, Barsch, said Sessa, who has cerebral palsy and an intellectual disability, has trouble communicating. He was sent to the hospital for what appeared to be symptoms of COVID-19 with a high temperature and vomiting. He also had a bowel blockage, Barsch said, but doctors had to determine first if he had the virus. He was placed on a COVID-19 unit, but several days later his test came back negative, his mother said. Soon after, his bowel burst and he needed emergency surgery, Barsch said.

Now back home in Portland, she said, Sessa shows signs of anxiety, saying “no 911” or making the sound of an ambulance siren. When he hurt his toe recently, he had to be reassured that he wasn't going to be put in an ambulance and taken to the hospital.

“Middlesex did a great job with the medical care,” Barsch said. “But I should have been allowed to be with him.”

A spokeswoman for the hospital said in an email, “Due to federal privacy laws, we cannot comment, but please know that Middlesex Health goes above and beyond to provide compassionate care to everyone, and we adhere to all civil rights laws.”

### **‘The communication just really isn’t there’**

Maria Dadario, 27, of East Haven is also part of the complaint filed with OCR. Dadario, who is hard of hearing and has limited vision, went to the emergency room at Yale-New Haven Hospital on April 2 to receive care for some mental health symptoms she was experiencing.

She arrived by Uber and carried with her a pre-printed emergency information card which identifies her disabilities and says she requires a sign language interpreter.



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Yale-New Haven Hospital

But Dadario learned that no sign language interpreters were being allowed on site because of the restricted visitor policy.

Instead, the hospital offered her the chance to use remote video interpreting. But with her vision problems, Dadario could not see the interpreter on the screen clearly, and the equipment repeatedly froze,

the complaint says.

A psychiatrist came to see her, but she wore a mask, so Dadario could not read her lips or her expressions.

Dadario said recently, with assistance from an interpreter, that the experience was very frustrating.

“If you are really in pain or feeling emotional, how else do you communicate if you can’t speak?” Dadario asked. “They should have an interpreter instead of using (video remote interpreters). The service in the hospital is just awful, so it

freezes. The communication just really isn't there."

After three hours of "little to no effective communication," the complaint said, Dadario left the emergency department with instructions to follow-up with her own mental health provider.

The complaint said that Disability Rights Connecticut confirmed that outside language interpreters are not being allowed on site due to the hospital's COVID-19 visitor restrictions.

A spokeswoman for Yale-New Haven Health System said in an email that the hospital "respects, protects and supports each patient's rights, including providing meaningful access to those who may require interpretation assistance within the health system."

She said the health system continually seeks "to improve and update its processes, and as such we recently implemented COVID-19 communication cards for deaf and hard-of-hearing patients, the first institution in the state to implement such a valuable communication tool."

While in-person interpreters are always "the preferred option for consequential medical conversations at Yale-New Haven Hospital," the spokeswoman said, "augmentative services and new technologies are available to supplement the in-person staff when necessary, especially for unanticipated visits."

### **Voices for the voiceless**

A third complainant is a 73-year-old woman who went to Hartford Hospital on April 19 because of a kidney infection but was also quickly diagnosed with COVID-19.

The woman lost her short-term memory due to an aneurysm and several strokes 11 years ago and is mostly non-verbal.

During past hospital stays, the woman, who is only identified as "G.S." in the complaint, always had a family member with her who could inform hospital staff if the woman was feeling pain or discomfort, as well as help keep her calm during difficult procedures or tests.

But this time, with COVID-19 visitor rules, her family was denied entry.

Her daughter, who asked that the CT Mirror not use the family's name to maintain their mother's privacy, said medical staff missed cues and her mother panicked in a way she hadn't in the past. At one point, with her health

declining and her fear and agitation growing, the woman tried to bite a nurse during a painful test. As a result, the complaint said, she was tied down and sedated.

“Imagine someone with no short-term memory opening their eyes and people with masks and full gear are coming at you and inflicting pain on you. What would you do?” her daughter asked. “It’s like waking up and feeling like you’ve just been kidnapped. That’s the vision we had in our head because our mom has never been violent, ever.”

The hospital agreed to assign an employee to sit with the woman and provided an iPad so she could have two video calls a day with her family.

“Our goal was just to be able to have her have a voice—somebody to make sure that her wishes were communicated,” said the daughter. They tried, too, to help medical staff understand their mother’s signals but, she said, “You can’t teach someone in five minutes what took 11 years to figure out.”

As their mother’s health continued to worsen, and the family again asked if one of them could visit. This time the hospital agreed, but on the condition that the visitor – another of the patient’s daughters – not leave the room. If she did, she would not be allowed back in. This was unsustainable, and after 24 hours with her mother, she left.

Requests for a second relative to visit were denied, the daughter said, and their mother was intubated on April 30 as her health continued to deteriorate.

“We thought, at that moment, we were going to lose her,” said the daughter. “It was a really, really bad day.”

But after two weeks on the ventilator, just as the outlook seemed the most grim, the patient’s breathing strengthened. On May 19, she tested COVID-19-free. The hospital said two family members could take turns visiting.

Cushman said she was glad the hospital agreed to let the family members in, but it’s unclear whether this was an exception for this family or a new policy.

“*How do you get somebody to really understand the difference between being a visitor and being that communicator?”*

— Daughter of complainant ‘G.S.’

When asked to comment on this, a spokeswoman for Hartford Hospital emailed a statement that said, “As health care providers, our goal is always to ensure full and equal access to healthcare services and facilities for qualified persons with disabilities. At Hartford Healthcare, a support person is allowed to accompany a patient with a disability when required.”

When asked to clarify the policy and explain whether this meant the visitor could not leave the patient’s room or would not be allowed back in, the spokeswoman did not respond.

“They consider you a visitor,” the daughter said, “but with my mom, it’s not just visiting. It’s her connection to the outside world. How do you get somebody to really understand the difference between being a visitor and being that communicator?”



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**Kathleen Megan** Kathleen Megan wrote for more than three decades for the Hartford Courant, covering education in recent years and winning many regional and national awards. She is now covering education and child welfare issues for the Mirror.

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