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Advocates want parents of people with intellectual disabilities to be excused from Connecticut's no-visit rule at hospitals during the coronavirus crisis



By JOSH KOVNER

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After officials halted visitation at hospitals to slow the spread of the coronavirus, they recognized that the 5,000 people with intellectual and developmental disabilities who lived in group homes still needed to be accompanied by an aide from the facility during a hospital stay.

So an exception to the no-visitation rule was crafted, one in a series designed to find a balance in this overturned world. It would allow a caregiver from the group home to stay at the hospital, helping nurses and doctors treat these patients and to ease the patients' inevitable confusion and fear and possible decompensation.

But the exception was not extended to the larger population of 45,000 Connecticut residents with the same disabilities who live at home with their parents. Across the border in New York, the identical exception that covers group home residents also applies to those living at home.

Advocates in Connecticut are now requesting that the exception apply to every resident with an intellectual or developmental disability regardless of where they live — a position that parents fiercely support.

“They would have to drag me out kicking and screaming before I left her at the hospital,” said Lori Leskin of Westport, whose daughter, Sami, 24, has an intellectual disability and epilepsy, and does not speak. “They would have to call the police.”



Sami Leskin

A patient who can't understand what is happening and who can't communicate would not be able to comply with treatment without the reassuring presence of a parent or guardian, said Shannon Jacovino, head of advocacy and public policy for The Arc Connecticut, which is leading the call for the extension.

“We're all trying these things out on the fly — but to have this only apply to group homes is a concern,” said state Sen. Derek Slap, a Democrat of West Hartford and a member of the legislature's Intellectual and Developmental Disabilities Caucus. “Among those 40,000 people in the community, there is a wide range in the ability to communicate with health care providers. ... I reached out to my senate colleagues and to the governor and said, let's look at this and have a conversation and get it changed. The Lamont administration has been very open to making adjustments.”

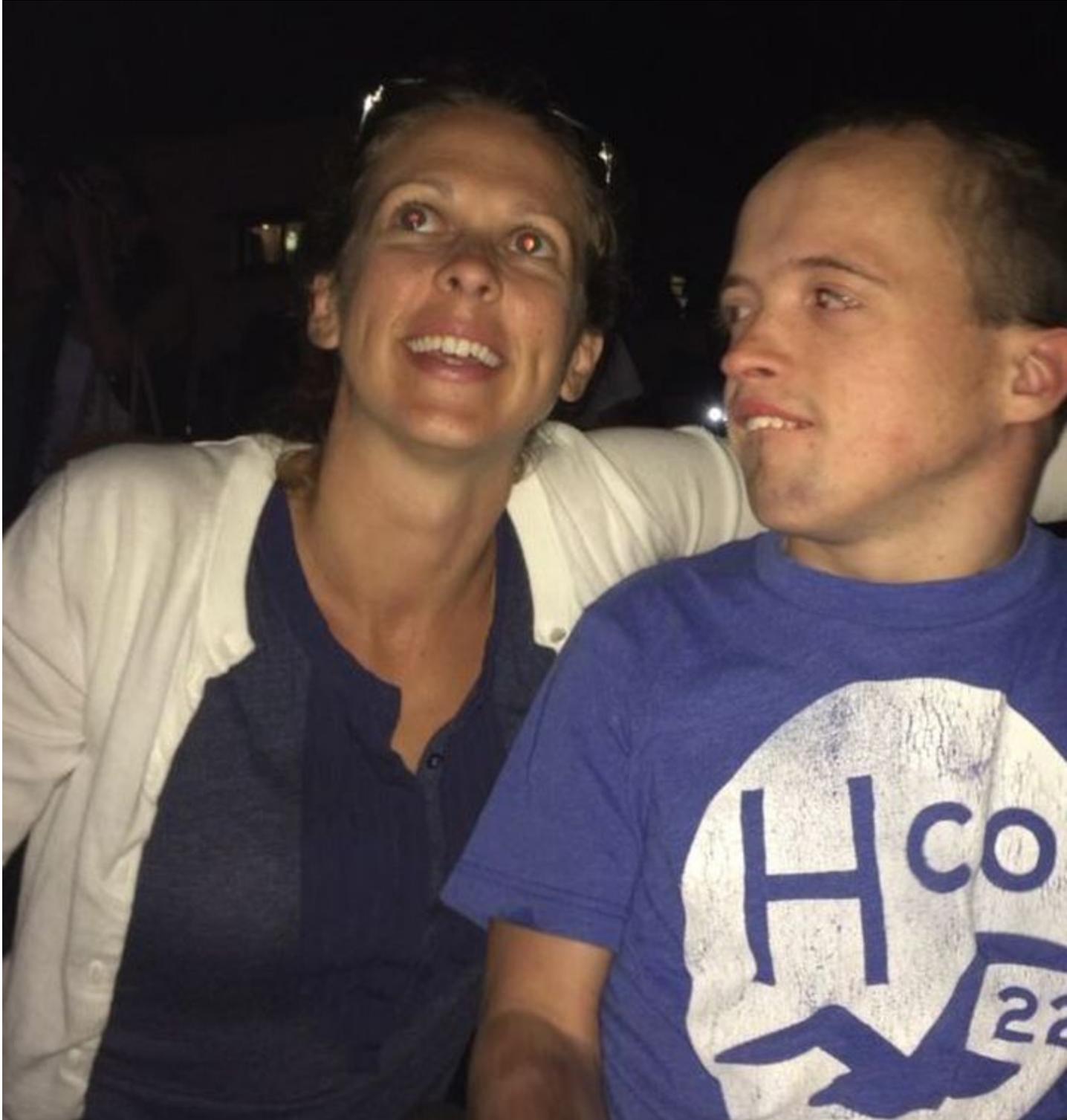
The state Department of Developmental Services, which serves 17,000 people with intellectual and developmental disabilities, supports extending the exception to cover every person in Connecticut with an intellectual disability. But hospitals, concerned about personal protective equipment, want to know what kind of masks parents or guardians would be required to wear under an expanded policy.

“Is a homemade mask acceptable?” said Krista Ostaszewski, spokeswoman for the Department of Developmental Services. “This is why we are having continued conversations with the Department of Public Health and the Connecticut Hospital Association. We want to see how we can come up with a way parents and guardians can accompany [sons or daughters] to the hospital, and we want the hospital staff to feel safe.”

DPH spokesman Av Harris did not provide answers to inquiries from The Courant.

Jacovino said Arc and other advocates are being measured in their call for parents to be able to accompany their sons and daughters, in large part because state health and safety agencies are trying every day during this pandemic to save lives and health.

Parents are also appreciative, but they are terrified of their intellectually disabled son or daughter becoming sick and having to go to the hospital alone.



Kate Haaland and her son, Chris Horwath

“We’ll make our own masks — coming up with PPE is the least of my problems,” said Kate Haaland of Waterford, whose son, Chris, 25, has an

intellectual disability and is nonverbal. He is legally blind and deaf and communicates with gestures, facial expressions and some sign language. “It’s really important for him to have someone there who can read him,” Haaland said.

Chris has not been outside for more than a month, his mother said.

“I can’t let him get sick,” she said.



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“A trip to the hospital would be over-the-top traumatic for him,” Haaland said, explaining that Chris becomes self-injurious and combative in stressful situations.

“He has to be held down, and I have to lock eyes with him. If I can do that, then he knows he’s fine and he will tolerate it, knowing he is loved, safe.”

Leskin said Sami was sick with a horrendous case of the flu last year and spent seven weeks at Norwalk Hospital with a tracheal tube. Leskin spent 46 nights at the hospital. She was able to inform staff members about Sami’s seizures as they occurred and help with her care.

“She looked at us with such fear in her eyes,” Leskin said. “There was no way I was going to let her wake up and not see me.”

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Josh Kovner covers child protection and social justice. He was part of the Pulitzer-winning team coverage of the Lottery shootings, and of the Pulitzer-finalist team coverage of the Sandy Hook school shootings. A story on a boy with autism, "Saving Evan," won a national award. Kovner is an adjunct faculty member at the University of New Haven.