

Maine man evicted for using pot to calm his seizures now calls hospital home

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By Eric Russell

SKOWHEGAN — For two months, Mark Madore has called the emergency department at Redington-Fairview General Hospital home.

There are two twin mattresses on the floor in a small room where he spends most of his time – asleep and awake. Two more mattresses are attached to the wall with athletic tape to protect him when the seizures come. A small whiteboard hangs on the wall that lists basic information, including the hospital staff member assigned to him any given day.

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Under the “notes” section are three words that have been there since he arrived: “Waiting for placement.”

Madore, who is diagnosed with neuromuscular disease and seizure disorder and has intellectual disabilities, is among hundreds of disabled adults who receive residential services under a MaineCare program known as Section 21.

Until recently, the 34-year-old had lived in a group home in Embden for about a decade. He was abruptly evicted in July after he started using medical marijuana to treat his seizures, which was not authorized by the home that provided his care.

His mother, Cathy Madore, said she takes responsibility for the medical marijuana, but disagrees with the outcome. She just wanted to help her son. Instead she left him homeless.

“Even a stray dog gets to go to a shelter,” Cathy said. “He’s a person.”

Maine’s system for providing services to adults with developmental disabilities has been fracturing for years, mostly because of insufficient funding and poor oversight. A [recent federal audit](#) revealed that the state failed to investigate a majority of critical incident reports for adults in residential facilities, including 133 deaths over a 30-month period from January 2013 through June 2015.

Officials with the Department of Health and Human Services have both downplayed the report’s findings and insisted the system has improved, but providers, families and advocates don’t believe that’s true.

Madore’s ordeal is a good example of how broken the system has become. Although his diagnoses entitle him to services, there has been a constant shortage of funding, which has led to a shrinking number of group homes, leading in turn to longer wait time for people trying to get in. As of Aug. 31, there were 1,631 adults with developmental disabilities on a waiting list for residential services. Some will wait years.

And if Madore’s family wants him to continue using medical marijuana – as his doctor has recommended – that could complicate things further. The program that provides his services is federally funded, but in the eyes of the federal government, marijuana is illegal. That conflict has not been tested in court.

‘IT’S REALLY NOT WHAT WE’RE SET UP TO DO’

For now, he'll stay in the emergency room.

Cullen Ryan, who chairs the Maine Developmental Services Oversight and Advisory Board, leads an advocacy group called Maine Coalition for Housing and Quality Services and has a disabled son, said he doesn't know how common it is for people to be housed in emergency rooms.

"We certainly know families are concerned about the adequacy of the crisis system and this clearly speaks to that," he said.

Jeff Austin, vice president of the Maine Hospital Association, said his organization doesn't keep data on emergency room stays for patients with developmental disabilities or behavioral problems, but he described it as a "huge issue" across the state.

A DHHS spokeswoman did not respond to questions about whether the state tracks residential clients who might be in emergency rooms.

But John Comis, the medical director for the emergency department at Redington-Fairview, said his hospital has accepted patients like Madore more frequently than people might realize.

"It's wonderful that we're able to do it, but it's really not what we're set up to do," Comis said. "Frankly, it's horrible that we even have to."

It's also enormously costly. Hospital officials estimated that the cost of care for someone in the emergency room is between \$1,800 and \$2,000 per day.

That means that for the 60-plus days Madore has occupied a room there, it cost a total of between \$108,000 and \$120,000. That's more than the cost of residential services for adults like Madore for an entire year.

STATE'S PROGRAMS FOR DEVELOPMENTALLY DISABLED

Cathy Madore has visited her son almost every afternoon at the hospital.

It's more than a half-hour drive each way, and she has had to cut back her hours at work – she's an education technician for a local school – but she does it.

The staff at the hospital is great, she said, but she's noticed changes in Mark. He doesn't sleep or eat well. He is more subdued, largely because of medication he was given to limit his aggressiveness.

Hospital staffers aren't trained to manage his behavior, Comis explained.

Multiple times, he has bumped his head, sometimes hard enough to draw blood.

Cathy, whose voice is constantly weary, said she and her husband, Norm, cared for Mark in their home in Belgrade when he was younger. He attended public schools and received special education services that included one-on-one care. He was safe.

But eventually he aged out of the services inherent in a school setting. Cathy and Norm both worked, and Mark couldn't stay home alone. So they applied for residential services through MaineCare for adults with development disabilities.



Norm and Cathy Madore pose in their Belgrade home. Their developmentally disabled son, Mark, has acute care needs that the working couple cannot provide, so when he was evicted from his group-home setting, the hospital emergency department became his last resort. *Staff photo by Brianna Soukup*

The state manages two programs that provide the bulk of care for this population. Section 21 places adults in residential settings – often small group homes – with integrated care depending on their needs. Section 29 is for families who receive services in their own home.

For years, the state has struggled to manage resources for this population. Both programs are costly – an average of \$100,000 annually for Section 21 and \$22,000 for Section 29 – and even though federal law mandates that services be provided, wait lists have been common, particularly for Section 21.

Three years ago, the state settled a lawsuit filed on behalf of dozens of clients to clear the wait list for the highest-priority clients, but that didn't fix the larger problem.

When Cathy Madore first applied for residential care for Mark, around 2004, the process was easy. There was no wait list that she remembered.

DOCTOR SUGGESTS TRYING MEDICAL MARIJUANA

It took a couple of placements before Mark found the right fit. He was kicked out of one home because of violent behavior, but the Madores were able to find another option.

He settled in at a group home in Embden, shared by three other adults. It was staffed 24 hours a day.

The direct care workers at Mark's group home treated him like family. Cathy said some of them even visited him in the hospital.

But his seizures were still problematic. Cathy feared that every major episode meant further loss of cognitive functions.

She met with her son's primary care doctor this spring and he suggested a new medication: marijuana.

Patients with epilepsy have been using medical marijuana to treat seizures, and recent studies have suggested it's effective. It was worth a shot, Cathy figured. But how could she try it without jeopardizing Mark's care at the group home?

She pulled aside one of his workers, someone she knew would be discreet, and they agreed to administer the marijuana – authorized by Mark's own doctor – on a trial basis in late May and early June.

The owners of the group home, MAC Residential Services, found out and evicted Mark. Steve Austin, the chief operating officer for MAC Residential, explained that the violation put staff and other patients at risk and also threatened federal funding. The worker who administered his medical marijuana was fired as well.

Austin said it is upsetting that Mark has been forced to stay at the hospital.

"We wanted to continue with Mark. He was with us for a long time," Austin said.

With the benefit of hindsight, Cathy acknowledged she may have made the wrong decision. But now, Mark hasn't been adequately treated or staffed for weeks.

Ryan, the advocacy group leader, said if individuals go without adequate services, they can atrophy and even deteriorate to the point where they might need more care.

"Some may not come back from that," he said.

ADVOCACY GROUP CITES CONFLICT OF INTEREST

Mark was served with an eviction notice July 1 and had until the end of the month to leave. He didn't make it to the end of the month at the group home.

On July 25, he met with his neurologist, who decided to keep him at the hospital in Skowhegan. By the time he was cleared to leave, though, he couldn't return to the home.

The only other option was to return to his parents' home in Belgrade, but Cathy and Norm both worked and he needed more acute care.

They tried to get the group home owners to reconsider their decision and even reached out to Disability Rights Maine, the group established to advocate for individuals like Madore, but were told nothing could be done. Cathy was told they couldn't help because of a conflict of interest.

Kim Moody, the executive director of Disability Rights Maine, couldn't talk about the Madores' case specifically or explain what the conflict was but said they do happen.

So Mark stayed in the emergency department.



Cathy Madore grasps Mark's hand as he reaches out recently. She says his doctor recommended the use of medical marijuana, but as a result her son was left homeless.

Comis, the medical director for Redington-Fairview's ER, was careful not to discuss the specifics of Mark's care but said he's sympathetic to the family's concerns. He also said Mark is not the only adult with developmental disabilities who has ended up unexpectedly in his emergency room.

"If people are ending up here, that certainly seems like the byproduct of a broken system," Comis said.

If adults are on a waiting list but their current living situation – often their parents' home – becomes unsafe, they can end up at a hospital or sometimes a psychiatric institution like Spring Harbor in Westbrook or Dorothea Dix in Bangor. If they are abruptly evicted, like Mark, the same thing can happen.

The Aug. 10 audit by the U.S. Department of Health and Human Services' Office of Inspector General revealed systemic problems with the state's oversight of the residential housing program for adults with disabilities. DHHS officials have said things are vastly improved since the inspector general's period of scrutiny – January 2013 through June 2015 – but advocates like Ryan say the problems go deeper.

A SENSE OF URGENCY? ONE EXPERT SAYS: 'I WOULD HESITATE TO SAY'

Funding remains the biggest barrier. Providers – the small agencies that manage group homes and provide direct care services – are receiving less in MaineCare reimbursement than they did a decade ago.

Lawmakers did discuss a bill last session that would have increased funding significantly for the Section 21 program.

By increasing reimbursement rates, providers say they could afford to pay workers who staff the group homes a

higher wage, which would in turn make it easier to find and hire qualified candidates. Higher rates also would make existing group homes more financially stable and able to expand, thus reducing the waiting list.

The original amount requested in the bill was \$65 million in the first year and more in subsequent years, indexed to inflation. DHHS's recommendation was \$26 million, which would bring reimbursements rates back to 2007 levels, plus a 10 percent increase.

Neither passed and the bill was carried over.

Lawmakers did include an extra \$11.25 million in the current budget to be split between Section 21 and Section 29 services, but the state has yet to finalize the new rules for either, so that money is dormant.

"I would hesitate to say whether there is or isn't a sense of urgency," said Jennifer Putnam, executive director of the Progress Center, a Norway-based provider, and recently elected president of the Maine Association of Community Service Providers. "The department hasn't really been communicative with us on this."

Emily Spencer, a spokeswoman for DHHS, said in an email that the new funding hasn't been released because the state needs to finalize the rulemaking process. She didn't say how long that would take, although DHHS officials have told providers they are working hard to expedite the process.

But they also seem to acknowledge that the additional resources aren't enough.

Emily Kalafarski, acting associate director of DHHS's Office of Aging and Disability Services, said at an Aug. 14 meeting with the Maine Coalition for Housing and Quality Services that "for things to change significantly it would depend on the Legislature and the governor to appropriate more funding."

In the meantime, many group homes have closed within the last year. Those that haven't still struggle to find well-qualified staff because they can't pay much and can't offer adequate training.

FOR THE MADORE FAMILY, IT'S BACK TO SQUARE ONE

Stuck in the middle are the vulnerable Mainers like the Madores.

A little more than a week ago, Cathy got what seemed like good news: There was a crisis bed for Mark. It was in Bangor, but he could go immediately and stay until a permanent house could be found.

Cathy and Norm moved him in on Friday, Sept. 8, and stayed the night in Bangor so they could check on him the next morning.

"I'm not sure he knows what to think at this point," Cathy said that Friday. "I guess we'll just have to wait and see."

By Saturday he was already gone. Staff had to admit him to the emergency room again. He was hurting himself, and they couldn't restrain him, Cathy said.

He stayed in Bangor for a few days before returning to the emergency department at Redington-Fairview in Skowhegan. Back to square one.

Cathy said she doesn't know if she's more angry or sad.

"We're powerless in all this," she said.

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