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Mentally ill patients face spartan conditions, long delays in New Hampshire

By SARAH PALERMO

Joshua Knight was alone, had been for hours. He curled up on the mattress on the floor, shut his eyes and tried to block out his memories of the day.

Knight, 33, had been handcuffed and dragged out of his basement apartment in Chichester that September day last year. His mother, Carla Northrup, had been crying so hard the police told her she had to leave because she was upsetting him even more.

She hadn't been to see him at Concord Hospital where the police had brought him, not yet. So Knight was alone.

He had a mattress, bolted to the floor. A plastic cube served as a hard, backless chair. A television glowed behind a plastic window. At least the staff was kind enough to leave him the remote, he remembered four months after his three-day stay in what is known as Yellow Pod, a handful of rooms at the hospital staffed by Riverbend Community Mental Health.

For the first two days of his stay at Yellow Pod, Northrup called the hospital to check on her son. Hearing it could be several days more before a bed was available at New Hampshire Hospital, the state psychiatric facility in Concord, she visited to drop off clean clothes and magazines.

The room smelled of urine; Knight was unresponsive, curled up on the mattress so tightly his wrists hurt for weeks after from being tucked into his chest.

Doctors would come and go, assuring him they were working on getting him to the state hospital. He didn't believe them. He couldn't go outside for three days, until he was transferred to the state facility.

"It's really frightening," he said. "I was locked up in this little room, this tiny cell. I was treated like somebody who couldn't take care of themselves. Like an animal."

Knight, who suffers from depression and anxiety, was alone, but his experience is not singular.

One weekend last month, 44 people, including 18 children, waited in Yellow Pod or other hospital emergency rooms – where they were kept safe, sometimes sedated – until they were either transferred to New Hampshire Hospital for treatment or sent home because they were no longer deemed an imminent threat to themselves or others.

The wait times, many as long as Knight's and some even longer, are further evidence that the state is compromising care for some of its most vulnerable citizens, say advocates who are pressing the case for systemic changes in services for the mentally ill. Daily reports of the number of people lingering in emergency rooms have resonated with Gov. Maggie Hassan, whose budget proposal would add \$28 million into the mental health system over the next two years to provide more options for care. Yet, despite that proposal, providers aren't overly optimistic.

"You can't just add some care without rebuilding the infrastructure," said Dennis MacKay, executive director of Northern Human Services, which serves the mentally ill in the North Country.

The number of available beds at the state psychiatric hospital in Concord has fallen from 252 in 2010 to 130 today as state budget cuts required it to close parts of the facility. Twelve more beds are to be added at the state hospital this spring, but care providers say that doesn't address the reason more

people – nearly 41 percent more in 2011 than in 2002 – are seeking or requiring emergency hospitalization.

The National Institute of Mental Health recognized New Hampshire as a model of mental health care in the late 1980s, after the state downsized the sprawling state mental institution and sent more patients into community settings. Keeping people in their communities, even when they had experienced a crisis and needed to be involuntarily committed, allowed them to maintain ties with their support networks. When everyone has to go to the state hospital, they could be hours away from family and friends, the people who help them recover.

But low state and federal reimbursement rates from Medicaid made psychiatric services in local centers an unsustainable investment, and the number of involuntary-admission beds available outside of New Hampshire Hospital went from 101 in 1990 to eight in 2008.

In 2008, state officials and mental health experts crafted a 10-year plan to reinstate quality, community-based care for the mentally ill. It called for 12 assertive community treatment (ACT) teams to respond to patients in crisis and prevent hospitalizations. Most of those teams were never established or never funded for 24-hour coverage. The plan also called for 132 new residential treatment beds, which haven't been established, either.

The Disabilities Rights Center, dozens of families and the federal Department of Justice filed a lawsuit last year that alleges the stagnation and degradation of community-based care has led to unnecessary institutionalization of the mentally ill.

In the suit, Amy Messer, legal director for the center, alleges the state has chosen to fund the state hospital over community-based services, sacrificing patients' rights and freedoms along the way. While she was pleased with the governor's proposals, she would not say whether they could affect the suit. "The question remains whether we'll have the right mix and sufficient capacity of services to end the needless institutionalization that currently exists," she said. "We hope to work with the governor and the state to really craft a positive, meaningful and lasting reform."

In the meantime, Knight and other New Hampshire residents with mental illnesses say they would hesitate before reaching out for help from emergency rooms.

"I don't know what I'd do if I had to go back there," Knight said. "I'd never volunteer (to go). I think, if I had the choice, I'd keep my mouth shut and wonder about my sanity."

Even though Concord Hospital has spent more than \$1 million to create and staff Yellow Pod for crises like Knight's, Louis Josephson, CEO of Riverbend, said he isn't surprised to hear families are disappointed and angry.

"I would be shocked if we got positive reviews from Yellow Pod. . . . We're doing what we can do, but we're not an inpatient unit, and we're not going to transform ourselves into an inpatient unit when we've got empty beds a half a mile away at New Hampshire Hospital. We keep people safe, and provide some medication if that's appropriate, but people who need the state hospital need the state hospital," Josephson said.

"The only thing we could do is to say we don't have the legal authority to hold you, which we don't. Only New Hampshire Hospital has that legal authority. But we won't say that. We're not going to discharge people who are a risk to themselves or others. . . . I don't like the way I feel when I go to work. The consumers don't like it, and they shouldn't. No family member should."

Stranded in the ER

Community-based mental health care is supposed to prevent crises like the one that landed Knight in Concord Hospital last fall.

Between counseling, psychiatric treatment, peer support, supported employment and social engagement, among other services, the system was designed to help people with mental illness manage their diseases and live as independently as possible.

Community-based care is also a far less expensive method of treating mental illness: It costs \$44,000 a year for community-based treatment versus \$287,000 a year to treat a patient at the state hospital, according to a 2011 report by the federal Department of Justice.

Jeffrey Fetter, president of the New Hampshire Psychiatric Society, said that when he was a doctor at Concord Hospital, he saw firsthand how the lack of fully funded assertive community treatment teams left people stranded.

“They’re designed to keep really sick people out of the hospital, so they have to be available. It was not uncommon for a sick person to call on the weekend, and for there to be no (New Hampshire Hospital) bed. And the ACT team did not have staffing to ensure their safety, so there was no choice but to observe them in the emergency room,” Fetter said.

Thirty-five-year-old Edward lives in Allenstown. He asked not to be identified by his last name because of the stigma he feels from neighbors who have learned of his post-traumatic stress disorder, anxiety and depression. He’s been dealing with the state mental health care system for more than 20 years. When he was younger, in the 1990s, he saw more options for people in need of care; since 2002, he’s spent several days waiting eight or nine hours in hospital emergency rooms, seeking help.

In 2010, his father was sick, and he asked his psychiatrist several times for a referral to a counselor so he could deal with how the experience was triggering his illnesses. The referral never came, and one day Edward found his father dead. In crisis, he checked into the emergency room.

“The state makes it feel like it’d be easier to kill yourself than to get help,” he said. “To get help, you know what’s involved and you know it’s not always that nice.

“It’s frustrating. It builds anxiety because you’re just sitting there. If you know the system, you can tell them it was a misunderstanding and they just let you go when you don’t feel like waiting there, getting worse.”

‘If only I had known’

Laura Foster-Bobroff knew of New Hampshire’s status as a model of mental health care. She thought she had done everything she needed to do to ensure that her daughter would achieve adult independence in a system that understood her needs.

Her daughter, who has asked not to be named in this story, has a complicated diagnosis of mental illnesses and learning disabilities. But Foster-Bobroff and her husband fought to get her the best education possible.

She spent her high school years living in Pennsylvania, the only place her parents could find an appropriate boarding school where she could learn to manage her illnesses and function in society. She lived first in a dorm, then in an apartment. She was given supported employment opportunities at a mall, and eventually worked independently.

The goal, Foster-Bobroff said, was for her daughter to build up to full-time employment. By the time she was 25, maybe 26, she could even be living in an apartment of her own. She’d still need counseling and support managing her finances and making big decisions, but she could be independent and productive.

When her daughter was ready to return to New Hampshire, members of her juvenile mental health care team asked Foster-Bobroff if she wanted to secure a guardianship so she could continue to oversee her daughter's case management and care.

"I said, no, I think we'll be good," Foster-Bobroff said. "If only I had known."

Her daughter, who is now 27 and unemployed, lives at her mother's home in Derry, but she has no legal guardian to help her navigate the mental health care system.

Foster-Bobroff is now pursuing legal means to reinstate herself as a guardian, and she hopes to join the Disabilities Rights Center in its suit against the state, or initiate her own lawsuit to protest inadequate care that failed to prevent her daughter's hospitalizations.

Her daughter was hospitalized once before high school, at age 12, following a major depressive episode. Since coming home from Pennsylvania at age 21, she's been hospitalized at least four times, maybe more. Foster-Bobroff doesn't know for sure, because without guardianship, she can't access her daughter's records.

At least once, her daughter was hospitalized after experiencing lithium toxicity when she started a new prescription. Noticing the symptoms, Foster-Bobroff tried to call the emergency team at a community mental health center. No one answered. Her daughter called, and still no one answered.

They went to the hospital, where hospital staff tried to call, and even they couldn't get through.

"How can you issue a medication and then not have anybody on call to take an emergency call?" Foster-Bobroff said. "It's ridiculous and it could result in a fatality in the right circumstances."

As described in the 10-year plan, the mental health system is supposed to create a multi-layered cushion – including supported housing and consistent outpatient services, ACT teams and inpatient beds in local communities in case of crises – to prevent people from needing institutionalization. Instead, the job is falling on families to handle alone.

Foster-Bobroff plans activities with her daughter where she can demonstrate positive life skills like budgeting and planning.

"I'll be honest, I'm in my 50s. I'm tired. I'm tired of being a caretaker. I did my stint. I did everything I was supposed to do. I invested everything I had and then some to get my daughter to the point where she could be a functional adult, and the system has let me down.

"But nobody cares about the crazy people. That's how it feels when you're in the system."

She lays the blame for her daughter's regression at the feet of her local mental health center and the state budgets that have starved the center of funding.

Her daughter has had five therapists in the past three years because of the high turnover at the local center.

Edward of Allenstown says he's worked with three doctors and three nurses in the last two years.

"The turnover is so frustrating. If you have a counselor, you have to first go through your whole life story, and then they quit, and you get a new one, and you go through your whole life story again. It's like you don't make any progress," he said.

He has had the same case manager for two years and can't bear the thought of what it would be like if she also left.

"That would be devastating," he said. "She knows me."

Mother's vow: never again

Knight's mother, Carla Northrup, like Foster-Bobroff, has organized her life to provide constant support for her adult child. She works nights; her boyfriend works days. They involve Knight in vacation planning, household errands, chores.

There's no one else.

"I worry that when I'm gone, Joshua will go away," she said.

She doesn't mean he'll go missing, live on the streets or in the woods, as he did several years ago. She means she worries that he would kill himself if he lived alone.

Northrup and Knight both say if they feel a crisis coming, they might turn to a church next time – even though they don't belong to a church or have faith that the people there would know what to do.

"But I don't think they'll lie to me," Northrup said. She found out on Knight's second day in Yellow Pod that he had been told she was the reason he had been sent there.

"It was an almost irreparable tear in our relationship," she said.

Yes, she had called the police after speaking with someone at Riverbend, where Knight receives counseling and other services. Knight had been increasingly depressed, not eating, not sleeping, and becoming more explosive in his reactions to the people around him.

At 6 feet 4 inches, "he's a gentle giant," his mother said. But when he put his palm against her chest and shoved her, she knew she needed help.

She thought Riverbend could connect her with someone who could talk with him. She didn't know the person she spoke to would be obligated to report the incident to the police. She didn't know that before help came, there would be a police search for her son, that he'd be handcuffed in the backseat of a cruiser when they found him, that he'd spend three days in isolation without treatment or medication.

"I can't imagine what it would take to force me to go back to Yellow Pod for help," she said. "I don't even think a gun to my head would force me to go."