Families of Violent Patients: 'We're Locked Out' of Care

By GARY FIELDS June 7, 2013 10:46 p.m. ET

SEATTLE— Suzanne Lankford for seven years has tried and failed to get long-term mental-health care for her son. When she hears news of a gun rampage or other violence, she gets chills.

"Whenever I see the parents saying they tried to get help, I think, 'That could be me,' " she says.

Ms. Lankford has watched her son, Joshua Rockwell, today 28 years old, barricade himself inside a room to ward off imaginary assassins. He once knocked her out with a blow to the head. She called the police on him after recognizing him in a mall security video of an armed robbery. Charges are pending.

He was later charged with attacking and harassing a nurse and law-enforcement officer. That trial has been delayed several times.

After Ms. Lankford's punch to the head, she asked her son's doctors about his treatment. She received a standard answer: Privacy laws prevent his doctors from talking to her without

his permission, because he is an adult. His lawyer declined to comment citing the pending charges. Mr. Rockwell, who is in custody, declined to comment through his mother under the advice of his attorney.

When America began dismantling its government-run mental institutions a half-century ago, the U.S. started creating privacy protections and made it tougher to forcibly hospitalize people. The goal was to allow the mentally ill to live something close to a regular life.

Today, after a series of high-profile shooting rampages, many with links to mental illness, the U.S. is re-examining this approach. Some of the loudest voices for overhaul are from the families of the mentally ill—a first line of defense.

"We have been asking for information on Josh's medications, on his treatment plan...so that we can help him meet those obligations, but we're locked out," Ms. Lankford says. "I don't know how this story ends."

In recent shootings, mental-health problems form a backdrop. Jared Loughner, who opened fire in Tucson, Ariz., in January 2011, killing six and badly injuring U.S. Rep. Gabrielle Giffords, had withdrawn from college after he was required to take a mental-health evaluation. Attorneys for James Holmes, who killed 12 people in an Aurora, Colo., theater last July, are seeking an insanity defense.

The shootings have led to discussions around mental health status and gun background checks. At least four states, including New York, proposed laws requiring mental health professionals warn third parties if a patient is believed dangerous. The New York law passed. Critics say it will prompt

patients to stay away from treatment.

Advocates for the mentally ill disagree on how to reconcile the tension between patient rights and public safety.

Confidentiality is vital to ensure patients seek treatment, says Ira Burnim of the David L. Bazelon Center for Mental Health Law, a Washington, D.C., advocacy group.

"The current system discourages patients" from seeking care because of the stigma of mental illness, says Mr. Burnim. He argues for a system of "assertive community treatment," in which therapists actively work with patients to help them build the habits needed to stick to their therapy. "The key is everything is done voluntarily, which means the patients buy into the treatment plan," he said.

Sandi Ando sees it another way. She says medical privacy laws prevent families from helping. The Health Insurance Portability and Accountability Act, or HIPAA, makes medical records private.

"HIPAA is the bane of our existence as parents," says Ms. Ando, the Washington state public-policy director for the National Alliance on Mental Illness, an Arlington, Va., advocacy group. Ms. Ando has two close family members who suffer from mental illness.

Today's system is a patchwork of state and federal laws and policies. Five states don't allow involuntary treatment. Nevada has a bill pending that will allow it, in some circumstances. The other 44 states, for the most part, have stringent requirements for involuntary treatment, according to the Treatment Advocacy Center, an Arlington, Va., research and advocacy

group.

Pennsylvania, for example, requires doctors and relatives seeking an involuntary commitment to demonstrate that the person is so unwell that within 30 days the patient will suffer death or bodily injury without treatment. Pennsylvania also sets the "age of majority" at 14, meaning an eighth-grader can block a parent from receiving information about his or her treatment.

"So you have a seventh- or eighth-grader making decisions on their mental illness. I wouldn't let a 14-year-old decide much of anything," said Rep. Tim Murphy, (R., Pa.) who has been holding hearings on mental-health privacy laws.

There are complexities, however. The Pennsylvania law was designed partly to ensure that juveniles can ask for mentalhealth treatment without waiting for a parent. For imprisoned convicts, there are stiff restrictions on forcible treatment as well.

In the early 19th century many mentally ill people were confined to jails. Activist Dorothea Dix in 1841 discovered the abusive system and worked to change it, giving birth to state mental hospitals.

Over the next century, the hospital population soared, topping 550,000 by the 1950s. But abuses there, including forced hospitalizations, as well as the introduction of new medications, led to dismantlement and a movement toward the modern approach of outpatient care. States passed laws to protect the civil rights of people released from hospitals and to make it tougher to force treatment.

Last year a division of the Department of Health and Human Services reported that 44.7 million adults—nearly one-fifth the adult population—experienced mental illness in 2010 ranging from anxiety to serious mental illnesses like schizophrenia. About 40% of the 10.4 million with serious mental illness didn't receive treatment, the report said.

Some cross into the criminal-justice system (whether as criminals or as victims) or into homelessness. Budget strains on some local treatment facilities are one reason for this. Another reason, relatives say, is that patients' families are locked out of the process.

Pat Milam, a businessman in Harahan, La., said his son grappled with mental illness from adolescence. Diagnosed as paranoid and schizophrenic, Matthew Milam, 24, once cut his own throat. Another time he dug a grave for himself in the backyard.

In October 2011 he was admitted to an Ochsner Health System facility in New Orleans and discharged eight days later—over the protests of his father, who assembled signed affidavits attesting to his son's behavior. Matthew Milam's longtime psychiatrist, Milton Anderson, who worked at the same facility, had written in reports that the young man was "a very high risk for suicide or other bad outcomes."

Pat Milam says he hand-delivered the documents to the doctors. "I didn't want them to say, 'We didn't understand you thought he was that dangerous,' " he said. Citing HIPAA, the staff wouldn't discuss his son's treatment, Pat Milam said.

What Mr. Milam didn't know: Professionals at the facility had noted "several days of escalating homicidal and suicidal

ideation." One nurse noted that Matthew Milam had "a suicide plan." The notations were in documents Mr. Milam by law couldn't access.

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—Suzanne Lankford

Nevertheless, doctors concluded Matthew was improving and could be discharged. According to treatment records later released to the family, the young man said he wasn't suicidal. Doctors thought he would stick to his treatment, Mr. Milam said.

The family brought him home. On Oct. 21, Pat Milam said his son offered to fix him eggs for breakfast, then went to his room. When his mother looked in on him, he was sitting in the closet. Pat Milam was about to call the police when he heard the explosion.

According to police reports, the young man had attached a shotgun shell to a 12-inch piece of steel pipe. He put it in his mouth and lighted a fuse attached to the shell through small holes he drilled.

A staff member at Dr. Anderson's office said the doctors at the facility aren't allowed to comment. An Ochsner spokeswoman cited privacy laws in not commenting on any details in Mr. Milam's case.

It is difficult to know how many families are blocked from helping with mental-health treatment of loved ones later involved in crime or other personal tragedies. Overall, there are about 6 million adults who suffer from serious mental illness who receive some care annually.

E. Fuller Torrey, founder of the Treatment Advocacy Center, said most mental-illness patients aren't violent. But numerous studies, he said, show that patients who lack treatment are disproportionately represented in categories including homelessness, incarceration, suicide and homicides. His group estimates some 216,000 of the U.S. homeless population, or roughly a third, are adults with untreated severe mental illness. It estimates there are 400,000 untreated adults in jails and prisons.

Washington state, where Mr. Rockwell lives, like many states began making it tougher to involuntarily commit someone in the early 1970s. Among other things, court reviews are required as well as a physician's examination.

State lawmakers have taken some steps. A new law this year will let authorities hold patients longer, once they have been civilly committed, if they are accused of a felony but are incompetent to stand trial. The state also passed a law, taking effect in 2014, that will allow the use of past behavior in some commitment decisions.

Mr. Rockwell's story began more than seven years ago when he showed up at a friend's house emaciated, afraid of water and food, his mother said. Police have taken him to emergency rooms twice after he phoned in to report the presence of suspicious people who were stalking him. The people were imaginary, his mother said.

Ms. Lankford said sometimes her son signs consent forms that

allow the release of confidential medical information. Often, though, he doesn't.

Kris Flowers, a spokeswoman for Western State Hospital, part of the State Department of Social and Health Services and a facility that treated Mr. Rockwell, said she and other employees couldn't speak about a specific case. In general, she said, the law requires a patient sign release forms each time they are admitted.

In 2009, as Ms. Lankford had lunch with her son in a restaurant, she says, he started talking about plots against him. He said that voices were telling him that said she was involved. He then struck her, knocking her unconscious, and called the police on her. He was arrested. She didn't press charges.

In December 2010, Ms. Lankford turned on the television to see a picture circulated by Lynnwood, Wash., police of a suspect in the August robbery of an elderly couple at knife point in an Alderwood Mall parking lot.

It was her son, she said. This time, Ms. Lankford called the police.

At this point, Mr. Rockwell slipped through a loophole in the state law. Because the state mental hospital wasn't able to stabilize his mental condition so that he could stand trial, the county dropped the charges against him in accordance with state law in cases where a person is found incompetent to stand trial.

According to court documents in Snohomish County Superior Court, Judge Eric Lucas ruled that because of "mental impairment" Mr. Rockwell was incompetent to stand trial.

However, the judge said, there was probable cause to believe Mr. Rockwell had committed the crime for which he was charged, "and as a result of a mental disorder" he "presents a substantial likelihood of repeating similar acts."

A separate health assessment, however, concluded that Mr. Rockwell wasn't an imminent danger. That meant, under state law, he couldn't be involuntarily committed to Western State Hospital.

Mr. Rockwell was released.

Ms. Lankford says the hospital released her son with \$40, directions to a shelter in Seattle, two weeks of medication and instructions to make it to a mental-health appointment.

Ms. Lankford says the family lost track of Mr. Rockwell for two days until another area hospital phoned them with a question about next of kin. Her son hadn't made it to the shelter, or the appointment. Instead, he had taken up in a bus station. Concerned employees there had called an ambulance.

The county refiled robbery charges in 2012, a move that can be taken if a defendant becomes competent. He was again placed in Western to get him ready. While there, he was involved in an altercation with a nurse and law-enforcement officer, authorities said. He was charged in Pierce County for the assault.

Ms. Lankford has written letters to many politicians and officials seeking help. In one response, Jess Jamieson, the thenchief executive of Western State Hospital, wrote in 2012 that he understood her frustration. "We all need to find a better solution that will provide real and lasting results to individuals

living with serious mental illness," the letter said.

Ms. Lankford said she understands the law. "I get it, but look what's happening here," she said. "People are being shot dead."