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U.S. mentally ill and their families face barriers to care

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By Sharon Begley

NEW YORK (Reuters) - Lori, a 39-year-old mother in New Jersey, would like to save for the usual things: college, retirement, vacations. But those goals are far down her wish list. For now, she and her husband are putting aside money for a home alarm system. They're not worried about keeping burglars out. They need to keep their son in.

Mike, 7, began seeing a psychiatrist in 2009, after one pre-school kicked him out for being "difficult" and teachers at the public school he later attended were worried about his obsessive thoughts and extreme anxiety. He was eventually diagnosed with bipolar disorder.

As she keeps trying to get help for him, "I am learning firsthand how broken the system is when dealing with mental illness," said Lori. (Surnames of patients and their families have been withheld to protect their privacy.)

"We fight with doctors, our insurance company, educators, each other; the list goes on and on ... It isn't even a system. It's not like there's a call center to help you figure out what to do and how to get help."

Last week, the National Rifle Association blamed mass shootings such as that at Sandy Hook Elementary School in Newtown, Connecticut, on the lack of a "national database of the mentally ill," who, it claimed, are especially prone to violence.

Dr. Paul Appelbaum, professor of psychiatry, medicine and law at Columbia University, disagrees, however. "Gun violence is overwhelmingly not about mental illness," he said. "The best estimate is that about 95 percent of gun violence is committed by people who do not have a diagnosis of mental illness."

But experts on mental illness agree with one implication of the NRA's argument: families trying to get help for a loved one with mental illness confront a confusing, dysfunctional system that lacks the capacity to help everyone who needs it - and that shunts many of the mentally ill into the criminal justice system instead of the healthcare system.

"Public mental health services have eroded everywhere, and in some places don't exist at all," said Richard Bonnie, professor of law and medicine at the University of Virginia. "Improving access to mental health services would reduce the distress and social costs of serious mental illness, including violent behavior."

Because mental health care is in such short supply, emergency cases receive priority. If a young man has a psychotic break and threatens his mother with a knife, "you can call the police and initiate an emergency evaluation," said Bonnie.

A psychiatrist called to the local emergency room may agree that the man is an imminent threat to himself or others, or cannot provide for his basic needs - the criteria for involuntary commitment in most states. Anything short of that and even someone with a diagnosis of severe mental illness cannot be involuntarily committed.

Critics argue that this emphasis on civil liberties lets dangerous people roam the streets, and cite numerous cases where it has been fatal. In October, for instance, a Tacoma, Washington, man who had been diagnosed with paranoid schizophrenia and was in and out of mental hospitals for years confessed to killing his father with a hatchet.

One lesson of such tragedies, experts say, is that psychiatrists' ability to predict who will be violent "is better than chance, but not much better," said Dr. Marvin Swartz, professor of psychiatry at Duke University.

Another is that the shortage of in-patient treatment has led everyone from judges to mental health professionals to look for any excuse to avoid committing someone involuntarily. There is often no place to put them, and admitting one patient means discharging another who might be equally ill.

"Getting people into hospitals is extremely difficult because of the shortage of beds," said Columbia University's Appelbaum.

The shortage extends to out-patient services, too, largely as a result of continuing budget cuts. Since 2009, states have cut more than $1.6 billion from such spending, found a 2011 report by the National Alliance on Mental Illness (NAMI), a nonprofit education and advocacy group. The result is "significant reductions in both hospital and community services," it said.

Connecticut, where Newtown is, is an exception. Its mental health budget rose from $676 million in 2009 to $715 million in 2012.

'THEY'RE ALL PSYCHOTIC'

More typical are Illinois (a reduction in spending on mental health of $187 million in that period), Ohio (down $26 million) and Massachusetts (down $55.6 million). "There's a waiting list for our program (in Boston) and it's hard to get in," said psychiatrist and NAMI medical director Ken Duckworth, who treats mentally ill patients.

There is room in his program for 60 people. The waiting list has 20, he said, "and they're all psychotic."

It wasn't supposed to be this way. The Community Mental Health Center Act, passed in 1963, called for federal funding of outpatient psychiatric facilities in towns and cities "so people would at least know where to start" when they or a family member needed a mental health evaluation or treatment, said Appelbaum. "It was supposed to be a single point of entry." But only about 650 of the 1,500 centers were built, and federal funding for staffing tailed off after four years when Congress did not appropriate more.

As a result, of the estimated 45.9 million U.S. adults 18 or older who had mental illness in 2010, some 11 million had "an unmet need for mental health care," estimates the Alliance for Health Reform, a nonprofit advocacy group.

One of those 11 million is Joseph. Even though he became violent, tried to jump out of a moving car, hit his wife and threatened to burn down their house, it was not enough to keep him in the psychiatric unit of their local New Jersey hospital.

He "cycled through the system," said his daughter. He went to the local emergency room five times, was arrested four times, went to the psychiatric unit three times, and spent 25 nonconsecutive days in a psychiatric hospital - all in three months in 2010.

Joseph's psychiatrist and family believed he should be in a state mental hospital, but his doctor did not show up to testify at a commitment hearing and the main evidence presented was a threatening letter Joseph had written to his wife. He was not deemed a danger to himself or others, and was released.

He did, however, cycle between jail and the psychiatric ward, making him one of many cases that "wind up in the criminal justice system instead of the healthcare system," said the University of Virginia's Bonnie. "Families watch their loved one unravel and can't get assistance, and then they get ensnared in the criminal justice system and can't get them out."

The difficulty getting outpatient care for the mentally ill is particularly widespread because most psychiatric hospitals were closed during the "de-institutionalization" of the 1960s and 1970s, an effort to provide more humane care than in the sometimes nightmarish wards.

One facility that closed was Fairfield Hills State Hospital, which opened in 1933, housed just over 4,000 mentally ill, long-term patients at its peak in the 1960s, and closed in 1995. It was located in Newtown.

"It's a metaphor for what we've done about mental health treatment in this country," said Duckworth. "A town that had a major treatment facility for 60 years has a mass shooting by someone who was mentally ill. We don't have a coordinated system of screening for, let alone treating, mental illness."

Even a diagnosis of mental illness with a possibility of harming oneself or others is no guarantee of help, even for young people.

"We estimate that fewer than one-quarter of the children, teenagers and young adults who have a mental health problem receive any treatment whatsoever," said Bernadette Melnyk, professor of psychiatry and pediatrics at Ohio State University College of Medicine. "And of those who do get treated, a substantial amount of the treatment is not the best, evidence-based kind."

For instance, a combination of cognitive-behavior therapy and medication is most effective at treating depression. "But very few patients receive the psychotherapy because we have such a severe shortage of mental health providers," said Melnyk.

Trying to get that help can drain a family emotionally.

'SOME SORT OF MONSTER'

"There are no professionals to help us with the tantrums or hysteria at the dentist or getting a haircut," said Lori, the New Jersey mother. "When Mike has a fit or screams obscenities in public, strangers assume he's a spoiled brat or some sort of monster."

"I worry that if he does not take good care of himself . . . well, let's just say that I can empathize with Adam Lanza's (the Newtown shooter's) family, too," she said.

To be sure, protecting the public from crime spurred by mental illness is only one argument for better psychiatric care. Every person who needs such care and doesn't get it is one more individual whose dreams of a full and productive life are shattered.

Virginia's Bonnie saw that firsthand when, after the 2007 Virginia Tech shooting rampage by Seung-Hui Cho, scores of families told him of their struggles to get help for loved ones with mental illness.

One young man, a brilliant college student and athlete, suffered his first psychotic break as an 18-year-old freshman and was diagnosed with paranoid schizophrenia. Robert was hospitalized nine times over 12 years, but when he attempted suicide after one stay his parents could not get him admitted again: he did not meet the "imminent danger" standard.

Feeling threatened by his "increasing psychotic behaviors," the parents told Bonnie, they called the police, who arrested and jailed Robert for breaking and entering the family home. Without treatment, his psychosis only became worse.

It is all too common for the mentally ill to wind up in the criminal justice system, not the health system, said Bonnie. "Families are suffering the consequences of the lack of mental health treatment all the time," he said. "Every once in a while they explode into public view" with a national tragedy like Newtown.

(Reporting by Sharon Begley; Editing by Jilian Mincer and Steve Orlofsky)