

The METROWEST DAILY NEWS

Stumbling in the dark: Critics say system is failing children with mental illness

By Jon Brodtkin / News Staff Writer
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Evan McNamara was born with a cluster of birth defects known as VATER syndrome, and needed four major surgeries to survive the first three years of his life.

Throughout that difficult time there was always a "road map," a plan to ensure Evan's survival, his mother, Maureen, says.

But when Evan began showing signs of severe mental illness just before the age of 3, there was no road map. Maureen said her family "stumbled through the dark" for seven years before finding proper treatment for Evan, an experience that convinced her the mental health system is failing the families that desperately need it.



"Every three to six months we would start out with what we thought was a new team of people who would finally help us get our son well. But nobody did that," said Maureen, who lives with her husband, Pete, their son Evan, now 13, and younger son, Marque, 6, in Westborough. "If this course of action were taken with Evan's physical disabilities, Evan would have died."

Maureen McNamara is one of many parents of mentally ill children and experts on mental illness who say getting access to critical services is, at best, a challenge.

Jack Rowe, regional director of child and adolescent services for the state Department of Mental Health, acknowledged in [a forum hosted last week by Wayside Youth & Family Support Network](#) that the state often falls short in providing mental health care.

"The mental health system, such as it is, is very fragmented," Rowe said during the forum at MetroWest Medical Center in Framingham. "DMH covers some diagnoses. Some diagnoses are covered by other agencies. And some diagnoses are covered by nobody."

The U.S. Surgeon General's office concluded in 2001 that 10 percent of children and adolescents suffer from mental illness severe enough to cause impairment, but each year fewer than 1 in 5 mentally ill children receives needed treatment.

Two reports by non-governmental agencies on Massachusetts, one focusing on kids and the other on mentally ill patients of all ages, have detailed significant shortcomings in the state's mental health services.

As the mother of a child who has suffered both extreme physical and mental illnesses, Maureen McNamara notes she is in a unique position to judge the disparity in services available to the physically and mentally ill.

Evan underwent three bowel surgeries and spinal surgery before the age of 3 at Children's Hospital Boston. From the time he was born in MetroWest Medical Center in Framingham, doctors had a definite plan for his care, she said.

But between the ages of 3 and 10, the McNamaras struggled to find treatment for Evan, who has been diagnosed with bipolar disorder, Asperger's syndrome, and post-traumatic stress disorder, Maureen said. The latter condition is a result of the surgeries early in Evan's life. Evan also developed characteristics of obsessive-compulsive disorder and depression.

Evan lost the ability to speak coherently, and communicated with sign language from age 3 to 6. Until he was 10, he didn't bathe or brush his teeth himself, and was often violent toward himself and others.

"I know there is a God out there, because if there wasn't he surely would have hurt himself or hurt somebody to the point of no return," Maureen said. "He would hit himself. He would kick himself. He would attempt to burn himself. ...I'd be beaten and bit and kicked and scratched."

But, Maureen says, a succession of doctors offered no clear diagnoses or successful treatment.

That all changed when Evan was 10, Maureen says. A social worker referred the McNamaras to a child psychiatrist at McLean Hospital in Belmont. The doctor at McLean was the first to tell Maureen her son needed a psychiatric hospitalization.

Evan spent three months in one of the most intensive units at Bradley Hospital in Providence, R.I., a stay Maureen says was covered in full by Harvard Pilgrim Health Care even though the hospital was out of state and out of the health plan's network.

Evan then spent one year as a residential student in the Walker Home and School in Needham, where he is now a day student.

Despite a setback one year ago in which he ended up in a locked psychiatric unit at MetroWest Medical Center in Natick for 3 1/2 weeks, Evan has improved substantially since his hospitalization in Bradley, Maureen says.

Maureen said she is sad about the years Evan lost to mental illness and is angry at the mental health system. That experience caused her to speak out at the Wayside forum.

"I can tell you the system is wrong," she said at the forum. "My son could have died were it not for the grace of God. ...We need to say we're not going to the back of the bus anymore."

Beth Fleahman, parent support coordinator for Wayside, also says there is a discrepancy between treatment of the mentally ill and physically ill.

"I think a lot has to do with the stigma," Fleahman said, recounting an experience with her son, Chase, 18, who has bipolar disorder.

About four years ago, he was brought into an emergency room twice within a couple months, once for a psychiatric emergency and once for a medical emergency, Fleahman said.

"The treatment was just so different," she said, declining to name the hospital. When Chase had his psychiatric emergency, it took longer to receive treatment and he was seen in a room that had dried blood on the walls, Fleahman said.

Complaints about care for the mentally ill are supported by at least two recent studies.

"Citizens of the Commonwealth with chronic mental illness still languish waiting for community based services, wander our streets homeless, fill up emergency rooms when preventive treatment should have been provided, and needlessly end up in the criminal justice system. This is a human travesty that is avoidable with adequate funding and services," states a report on Massachusetts mental health services issued by the National Alliance for the Mentally Ill.

The report, released April 28, says an estimated 20,000 people with severe mental illness are waiting for Department of Mental Health services. It also says more than 100,000 children and adolescents in the state have serious emotional disturbances, but the state provides care to less than 5 percent of them.

However, the Department of Mental Health is a "provider of last resort," giving care to those that don't get it through private insurance, schools or other sources, said Lester Blumberg, the agency's chief of staff.

He disputed NAMI's waiting list figure, saying the agency's waiting lists include 14,000 adults and 1,500 or so kids.

"We certainly recognize there are still unmet needs on mental health services and there's lots to do," Blumberg said. "We do think we, the Legislature and the community have made significant progress in attacking the problem."

Toby Fisher, executive director of the state NAMI chapter, said the mental health system has been inadequately funded nationwide since long before the recent economic downturn.

"Mental health services are dramatically underfunded," Fisher said. "We've had a shortage of mental health services for decades now."

It's even tougher for children in part because kids often don't receive clear diagnoses, creating roadblocks in getting insurance plans to cover treatment, Fisher said.

A report released in October 2002 by Health Care For All and the Parent/Professional Advocacy League said many Massachusetts families are unable to get adequate mental health services for their children.

"The children's mental health system in Massachusetts and across the country is in crisis. Families are reporting major difficulties locating and accessing services for their children and adolescents," the organizations concluded after analyzing responses to a survey of 301 families.

According to the report, one-third of respondents waited more than a year before receiving treatment as often as needed, 26 percent said their insurance often or always would not cover needed services, and 60 percent worried their children would hurt themselves or others because critical services aren't available.

The report also faulted schools for not adequately understanding mental illness.

Evan McNamara was "in and out" of schools for years, and was expelled from a specialized school in 2001 after the school psychiatrist couldn't handle him, Maureen said.

Despite Evan's progress, his mother sadly notes that had he received proper treatment from the time he was 3, he might today be attending Westborough public schools.

"Now our life is better than it was, but like I said... when Evan watches his younger brother do things, he'll say 'did I ever ride the carousel at the carnival? Was I ever able to take swimming lessons at the beach? Did you ever buy me a balloon?' And I'll say 'No, I was never able to do those things,'" Maureen said.

"I will never be quiet about it, because you know what, Evan felt more shame, self-hatred and guilt than any little boy should feel about an illness."