

BEAUTIFUL MINDS

A PARENT'S NIGHTMARE

By **STEPHEN ROW**
Staff Writer

Kathleen's story began during her daughter's freshman year at college in 1991 in Storrs, Conn.

She may have ignored the early signs, like the fact that her daughter, Amy, was isolating from her friends during her senior year in high school.

She also expressed a fear about going away to school because she was disturbed about the recent death of her maternal grandfather who passed away Aug. 20 of that year.

It was while she was away at college, however, that the bizarre behavior started.

It began with strange sleep patterns, accompanied with bouts of mania where she was doing "six or seven mile runs in the middle of the night," Kathleen said.

Amy started drinking that year, not an unusual occurrence for a college freshman. What was strange was her reaction to hangovers.

"She said, 'Being hung over is the most comfortable way I feel all week.'"

Amy made it through her freshman year, though the experience was "really frightening" for her mother.

When Amy arrived home that summer, it was obvious something was wrong.

She managed to hold down a job selling ice cream at a park, but when she was not busy at her job her "moods were weird" her mother remembers.

"It was like we had landed on the planet Krypton," she said, remembering the episodes where one minute Amy was screaming at her then spending hours or even days lying in bed.

One day Kathleen was browsing through a local library when she came across a book by Mary Ellen Walsh about families dealing with mental illness.

The author's words seemed to be telling her story.

"That's when I said to myself, 'My God, my daughter has a mental illness,'" she recalled.

For Kathleen the realization was devastating.

"I can remember screaming in the car," she said, describing her experience as one of grief and "over-

Mother recalls daughter's battle



Trentonian Photo/BOB CASTELLI
NAMI NJ consumer outreach liaisons Jay Yudof and Kathleen Considine.

whelming loss."

Like many parents, Kathleen's frustration was compounded by well-meaning family members who would minimize the severity of Amy's condition.

"She's just going through a phase," she remembered one grandparent telling her.

By the end of the summer her daughter agreed to see a psychiatrist. The doctor prescribed Ativan to relax.

The effect of the sedative on Amy was acute. It not only relaxed her; it put her into a virtual catatonic state.

"I called the doctor and said, 'The body lying on the bed in my daughter's room is not my daughter,'" Kathleen remembers saying.

Amy was admitted to a hospital where a psychiatrist advised the family that their daughter would be "OK in six months."

Unfortunately the doctor's prognosis was far from reality. During her stay, Amy became "floridly psychotic" her mother remembers, having "visions of Satan and God."

It was then that Kathleen ran into problems with the managed care system.

"Our insurance ran out," she said. Kathleen recalls running "down to the billing office" with her husband where an insensitive clerk told

them, "Your daughter will be in and out of hospitals for the rest of her life."

What followed was a string of hospitalizations, "some good, some of which were heinous," Kathleen said.

Amy didn't respond well to medication and in the end she agreed to undergo electroshock therapy.

Amy now lives in the Boston area where she works for a managed care company.

"I just couldn't be more proud of her," Kathleen said of her daughter.

Her mother's story, interestingly, picks up where her daughter's leaves off. Kathleen was so moved by the paucity of help offered families of consumers in the area of mental health that she decided to return to school and get her master's degree in social work.

The condition of "family therapy can be horrible," she said, remembering the fresh memories of hospitals, inept hospital clerks and insensitive doctors.

Her daughter teases her about her new line of work.

"Isn't it nice I gave you a second career," she said.

— Kathleen Considine now works as a consultant for the National Alliance for the Mentally Ill in New Jersey. She can be reached through NAMI NJ's offices at (732) 940-0991.

ABOUT THIS SERIES:

To date, this week's series have chronicled the lives of "consumers" those who suffer from mental illness.

Today, the seventh day in our series, our stories deal with two parents. Their stories are typical of many who have devoted decades of care for loved ones who are afflicted with a mental illness.

Often the mentally ill individual would not have received the treatment they needed without the love and energy given to them by such devoted and loving parents.

Dealing with agencies can often be maddening

By **TONY PERSICILLI**
Staff Writer

MOUNT HOLLY — For many people, the most frustrating thing about dealing with government agencies and organizations is being shifted from one place to another.

Call someone for help, get put on hold, transferred to another department and then informed you have the wrong person.

For people with mental illnesses and their families, it's even worse.

But there is help. Such groups as the Family Support Organization of Burlington County exist with the sole purpose of helping people with mental illnesses and their families steer through the maze of bureaucracy.

"We put families in the forefront," said Marlene Penn the executive director of FSO of Burlington County. "We create a place for them to be full partners, to have a say in the kind of help they get and where they get it."

A county-based, non-profit organization run by families of children with emotional and behavioral problems, FSO of Burlington County provides the system at all levels with a perspective that is uniquely family oriented, working to ensure that the system is family friendly and responsive to the needs of families and children.

Especially the children. "In the past," Penn said, "it was very difficult for families to be involved with their child's care. We're trying to make that easier."

Which is the whole idea behind Children's System of Care Initiative.

An initiative of the New Jersey Department of Human Services, CSCI aims to reform the way in which services are delivered to children with emotional and behavioral issues. It seeks to ensure that families can access the care they need for their children right within their own community.

It is not a child welfare initiative. It is not a mental health initiative. It is not a Medicaid initiative and it is not a juvenile justice initiative.

It is an initiative which crosses systems based on the needs of the child and family.

"What we help people do," Penn said, "is move toward self-empowerment, self-advocacy, being able to clearly articulate what their needs are and where to find them."

"Instead of telling them what they need, we ask them."

The first child signed up for "Children's Initiative" on Feb. 1, 2001. The program now has 180 consumers.

Since the program started, Penn said, the "Children's Initiative" has seen an increase in school attendance, an increase in the number of children who have returned from residential care facilities back into the community and a decrease in juvenile detention among the participants.

"The earlier a diagnosis is made," Penn said, "the better, because that means the treatment can start earlier."

"And the earlier the treatment begins, the better chance you have for success."

Mother has been helping son for 20 years

By **STEPHEN ROW**
Staff Writer

Like many parents who have had to care for a child with mental illness, Maureen's story begins in adolescence when her son first spent an extended period away from home.

"He was always a very happy, rambunctious kid who was well-adjusted," she said of her son, whom, for the sake of this story, we will call "Paul."

If there were any early warning signs, she didn't notice.

Indeed, Paul's high energy could be attributed more to his intense intellectual curiosity and high intelligence which was reflected in his superior academic performance.

Admittedly, "he had some trouble focusing on his homework," but otherwise Paul seemed like any other teen boy.

He was a "good student but all over the place" she said, again, remembering how unaware she was of the storm clouds which lay on the horizon of Paul's consciousness.

But when Paul went away to boarding school things changed.

His father was a foreign national and his parents thought it would be a good experience for him to take a year studying abroad.

Paul liked the idea too and before long the family was packing its excited son to school nearly 6,000 miles away.

It was in Paul's letters which he sent home where Maureen first noticed something was not right. Growing up in the home of a designer, Paul had always loved mechanical drafting. He had written in the neat block print characteristic of draftsmen in the days before CAD.

But now his letters were arriving home in barely legible scribbles. The content was similarly garbled.

His observant mother took notice. Still his grades were fine and half a world away in a day before the Internet, the telephone was the only other means of communication.

"He seemed normal on the telephone," his mother said, explaining why she and her husband decided

to let their son finish out the year uninterrupted.

When he arrived home that summer, however, things were decidedly different.

"He was in a state of mania," Maureen said.

Of course she didn't have those terms at her fingertips back then, but she knew she "couldn't talk to him" the way she used to before he left.

A skeptic might ask if this was just classic adolescent rebellion but Maureen was a conscientious mother who sensed something more was afoot than a mere identity crisis.

"He was not the son I sent away; he was beyond rambunctious," she said, struggling to find the words to describe what her mother's intuition told her.

He was still active but the joy of life was gone.

"He was not sleeping. ... He was not having a great time. ... He was cursing at me. [He was] everything that (Paul) was then but it was greatly intensified," she said.

The year was 1979 and like any

serious parent she posed the question.

"I asked him if he was doing drugs and he said, 'You know I've never liked the Grateful Dead,'" she said, managing a slight laugh.

"If I ever start liking the Grateful Dead that means I am on drugs," he told her.

He was crazy about Pink Floyd and would listen to it for hours on end.

As a mother, Maureen described her son's condition as being "like a cut which needed stitches," as something too serious for a mother or father to treat on their own.

"I knew I couldn't handle it myself," she said.

"I convinced him to go to a psychiatrist. He went two times and decided he didn't need this, so I want to the psychiatrist and said, 'Why don't you ask (Paul) to bring in some artwork?'" she remembered.

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