

Son's plight leaves mother frustrated

By JULIE MACK
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Gloria DeLillo told television reporters last summer she was ready to kill herself and her son, Joseph.

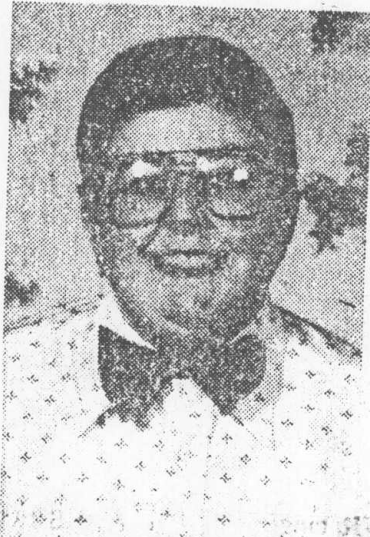
Mrs. DeLillo, a New Dorp resident, never acted on the threat. "My husband said it would be a silly, cowardly thing to do, and he's right," she said. "But I meant what I said at the time. I was just so frustrated."

It is a frustration which has fermented for 20 years, ever since Mrs. DeLillo learned that her son, Joey, was mentally retarded. In 1979, the DeLillos also learned that Joey suffered from a rare syndrome, Prader-Willi, that causes both behavior disorders and physical handicaps requiring constant supervision.

While Mrs. DeLillo's death wish has passed, the frustration still seethes. Her dramatic statement last July brought state and local officials running, but her attempts to find adequate care for Joey remain unresolved.

Her story illustrates the problems in obtaining a proper diagnosis, finding proper care, and negotiating a complicated system of services.

And Mrs. DeLillo would not describe herself as a sophisticated woman. She is an ordinary housewife and mother, married for 37 years to her
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Joey DeLillo

Mother

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husband, John. They live in New Dorp above the family's shoe store. There are two other children — a son and daughter, both in their 30s — and grandchildren.

Joey, who will celebrate his 21st birthday next month, was a change-of-life baby, Mrs. DeLillo said. "Sometimes I wonder about these movie stars, these famous women who are having babies when they are 40, 45 years old," Mrs. DeLillo mused. "They have beautiful babies."

"Why does God do this to me? Sometimes I think he must be very angry with me."

At 61, Mrs. DeLillo is frail-looking and obviously weary from the strain of coping with a handicapped child for two decades. She shakes her head with bewilderment as she discusses Joey's situation and the overwhelming array of social service agencies and professionals associated with the case.

But the bewilderment can be deceptive. Mrs. DeLillo is a strong woman, as proven by her attempts to find help, and she knows what she wants. The problem comes in obtaining those goals.

The DeLillos discovered Joey was retarded when he was 8 months old and suffering from the croup. A doctor was called in, and while examining the baby, he dropped a bombshell on the family. "I don't know if anyone ever told you," said the physician, "but you have a retarded child."

Mrs. DeLillo said she was determined to keep her child at home, and at first, it wasn't too difficult. Joey was a loving, affectionate boy and he appeared to enjoy his special education classes.

But there were hints of other serious problems, problems that grew worse as Joey grew older. There were temper tantrums so severe that Mrs. DeLillo had to splash water on her son to make him coherent. As he became older and tore through the house in mad rages, Mrs. DeLillo said, "there were times I would actually sit on him."

There was also the problem with food. Joey was a compulsive eater, and he never seemed to get enough. The family was forced to put locks on the refrigerator and they stopped putting canned goods in the pantry because Joey would break open the cans and gobble the contents.

The overeating problem was compounded by Joey's lack of physical development. He is only 5 feet tall now, with the physical maturity of a young boy, although he weighs 190 pounds.

Mrs. DeLillo figured that Joey suffered from a disorder in addition to his mild retardation. "I knew there was something else there," she said. "Teen-agers are moody, but not like that."

When Joey was about 11, Mrs. DeLillo took him to a clinic in Philadelphia in search of a diagnosis. After three weeks of extensive testing and "thousands and thousands of dollars," the

doctors found nothing.

The answer did not come until 1979, when Joey's doctor told the family he had heard about a little-known disorder called Prader-Willi Syndrome (PWS) and that Joey matched the symptoms — the compulsion for overeating, the problems with obesity, the physical immaturity and poor muscle tone, the temper tantrums, the retardation.

Through the doctor, Mrs. DeLillo found a support group of other families with PWS children, Prader-Willi Greater New York Association, whose help Mrs. DeLillo has found invaluable in recent years.

Less supportive were administrators at the Board of Education, who seemed unresponsive to Mrs. DeLillo's announcement that as someone with Prader-Willi, her son had special needs which were not being met.

The big problem was food. Other PWS parents warned Mrs. DeLillo that Joey's overeating and resulting obesity could lead to hypertension, diabetes, heart problems and episodes of breath difficulty and turning blue. In fact, Joey has developed severe diabetes and high blood pressure in the past few years.

But it has been difficult to keep Joey on a strict diet, said Mrs. DeLillo, in part because she could not monitor his eating habits at the Richmond Occupational Training Center, which Joey has attended since he turned 18.

"He would eat his lunch on the school bus and then tell the



John and Gloria DeLillo in their New Dorp shop.

S.I. Advance Photo by Tony Dugal

women in the lunchroom, 'My mother doesn't give me lunch.' They didn't know better, so they would give him more food," Mrs. DeLillo said. Other times, Joey fought or stole food from classmates.

There was also the matter of Joey's temper tantrums, which are characteristic of Prader-Willi patients. Mrs. DeLillo tried to get Joey psychiatric services, but the boy refused.

Mrs. DeLillo said there were times the tantrums at school

were so severe that school officials had to use physical force to get him to stop. "They didn't understand the syndrome and no way were they prepared to cope with it," said Rita Welch, president of the Prader-Willi Greater New York Association.

In 1980 the association suggested, and the DeLillos concurred, that Joey needed residential placement at a facility specifically geared for PWS youngsters. One such facility, Rhinebeck Country School, is in upstate New York.

The Board of Education, which had jurisdiction over Joey's case, disagreed. The Committee on the Handicapped determined that Joey's needs were being adequately met in the public school system, and they would not authorize funding for residential placement.

That stance, which the Board of Education has maintained for the past four years, particularly rankles the DeLillos and their advocates.

"They don't want to know about Joey's problems," Mrs. DeLillo said. "They are only in-

terested in his educational needs. After 3 p.m., they couldn't care less what happens to Joey."

Mrs. Welch said the committee acted "in ignorance," without any attempt to understand the unique problems experienced by Joey.

Mrs. DeLillo said she became so frustrated in her attempts to obtain help from the Board of Education that she started thinking about drastic measures that would call attention to the situation.

"I've been so depressed that I considered leaving my husband so they would be forced to help me," she said.

"I figured if I was alone and had to work, they would have to give me something. I told the woman at the Board of Education that, and she just didn't saying anything."

Then last July, Mrs. DeLillo announced her death wish during a rally at the World Trade Center.

(First of four parts. Tomorrow: Finding a place for Joey.)

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