



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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