

Time is against mother's special son

By JULIE MACK
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Gloria DeLillo says she never really meant to kill herself or her son, Joey.

But her threat last July finally focused attention on Joey's situation. The young man, who turns 21 next month, has Prader-Willi Syndrome (PWS), a rare disorder that results in mental retardation, physical immaturity and a dangerous compulsion for over-eating that can lead to serious health problems and even death.

For the past four years, Mrs. DeLillo has been unsuccessfully trying to place Joey in Rhinebeck Country School, a special residential facility for Prader-Willi victims. Not only did Joey need a restrictive environment to keep him away from food, but Mrs. DeLillo and her husband — both in their 60s — were cracking under the strain of caring for Joey in their New Dorp home.

Rhinebeck accepted Joey in its program, but the problem of paying the fees remained. Over the past several years, Board of Education's Committee on the Handicapped has repeatedly said that Joey's educational needs can be met in the city school system.

School officials said they were not obligated to resolve Joey's medical or social problems under state law. Because the committee did not approve Joey's placement at Rhinebeck, the state has refused to pick up the bills if Joey were to enter the

facility.

As Joey's parents battled with the Board of Education over the past several years, Joey's condition deteriorated. He gained weight — Joey is 5 feet tall and weighs 190 pounds — and developed diabetes and high blood pressure, two health problems associated with PWS.

Moreover, Mrs. DeLillo became increasingly distraught over her responsibilities, which include constant monitoring of Joey's food intake and dealing with temper tantrums, an other problem associated with PWS, which can start with little provocation.

In her desperation to obtain help for her family, she considered divorcing her husband, figuring that would make school officials more sympathetic to her plight. And then, during a rally at the World Trade Center last summer, she threatened to kill herself and Joey.

Although Mrs. DeLillo regretted the statement almost immediately, she later said her dramatic announcement brought results. "Everybody's been really nice to me since then," Mrs. DeLillo said.

While people were "nice," Mrs. DeLillo said they did little to place Joey in a proper program.

Then came a tragic, emotionally devastating incident: In November, Joey was sexually molested by male classmates on a deserted Staten Island Rapid Transit platform while coming home from school.

Mrs. DeLillo said Joey told his father about the attack that night, although Joey would not tell the names of his attackers. The boy only said, "I thought they were my friends."

The attack was never reported to police, in accordance with Joey's wishes, Mrs. DeLillo said, and the perpetrators never identified. But the attack was reported to school officials, who responded by providing Joey daily bus service to the Richmond Occupational Training Center.

Ironically, on the night of the attack, the DeLillos received a phone call notifying them that the Staten Island Development Center's (SIDC) respite center had agreed to accept Joey for temporary placement. An advocate for the DeLillos had been working on the placement for weeks.

"They knew I couldn't cope anymore," Mrs. DeLillo said, "although it was just a coincidence that the call came the same night as the other thing."

So Joey moved to Willowbrook, and his condition improved. His eating is now under supervision and the behavior problems have largely gone away.

His mother praises the quality of care at the center. "Nobody can say anything bad to me about that place," she said.

But Willowbrook is only a temporary solution at best — the respite center is not equipped for long-term care — and his case has apparently stalled again, even though another powerful advocate for the DeLillos, Assemblyman Robert Stranieri, has intervened.

Mrs. DeLillo turned to Stranieri in December, when she was still trying to place Joey at Rhinebeck Country School.

Anne Seery, an assistant to Stranieri, helped Joey get accepted at Rhinebeck, but she ran into problems over who would

pay the fees. Once again, the Committee on the Handicapped withheld its approval. Stranieri told Ms. Seery to stick with the DeLillos and figure out a solution.

But by now, Joey's case was becoming considerably more complex because he was nearing his 21st birthday.

When Joey turns 21 on April 4, the Board of Education's responsibility for Joey ends — and because of his placement at the SIDC, another agency entered the picture — the state Office of Mental Retardation and Developmental Disabilities (OMRDD).

Besides the complications of dealing with officials from two different agencies, the DeLillos and Anne Seery also face a race with time.

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