

Time is against mother's special son

By JULIE MACK

Advance Staff Writer

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 overeating 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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Rhinebeck only accepts people under 21, Ms. Seery discovered, although it can keep students past their 21st birthday until other "appropriate placements" are found. So Joey could stay at Rhinebeck for at least a year, but only if he enters the facility by April 4.

As Ms. Seery tried to sort Joey's options, she became mired in a sea of bureaucracy. The Committee on the Handicapped held firm in its conviction that Joey did not need residential placement. Ms. Seery turned to Arthur Webb, commissioner of OMRDD, who was sympathetic but still uncertain what his agency could accomplish without the help of the Committee on the Handicapped.

With Joey's 21st birthday only nine days away, the committee is no longer handling Joey's case. But now OMRDD seems to be floundering on the question of Joey's placement.

One OMRDD official, Mary Jane Barnett, said the department had decided to place Joey in a group home for the mentally retarded. Yet another department official, Barbara Hawes, recently told Ms. Seery that the agency is still considering three options in Joey's case: the Rhinebeck facility, a foster home and a group home. "Meanwhile, Joey's still at

Willowbrook," Ms. Seery said. "Everybody agrees it's an inappropriate setting, but he's still there. And nobody says he's going to a facility which gives Prader-Willi persons the proper controls.

"They talk about another placement, but when? Where? They talk about one place, and then someone from OMRDD says, 'No, wait a minute, that group home isn't going to be opening up on schedule.'

"They were talking about a home which is going to be built for persons with Prader-Willi, which, if all goes well, will open in April 1985. But that's if all goes well, which we know it never does. And what will Joey do until then?"

Ms. Seery said the problem isn't a lack of concern on the part of the people at OMRDD or the Committee on the Handicapped.

"Everybody's concerned. But they are afraid to act," she said. "Everybody says things like, 'I'll get you a definite answer on Friday, a definite answer.' And then on Friday, they give you three or four options."

Ms. Seery said the DeLillo case has become an obsession with her.

"I was told by different people that I had to be more objective about this," she said. "But I couldn't be that way. I put myself in her (Gloria DeLillo's) shoes. I thought maybe the problem all along has been that there are too many objective people out there."

Ms. Seery said she won't rest until she sees a promise in writing that Joey will be placed in an appropriate facility.

As for Mrs. DeLillo, she alternates between optimism and depression. Her greatest fear is that Joey will be sent back home. "What will I do with him?" she said. Her greatest wish is to see her son "settled."

"But I still feel like I'm hitting my head against a brick wall," Mrs. DeLillo added. "Nobody's moving."

(This is the second part of a series. Tomorrow: Who's to blame.)

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