

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