

Little change for handicapped youth

Little has changed for Joey DeLillo in the past few months.

The 21-year-old Great Kills resident, who suffers from a rare behavior disorder, graduated from the Richmond Occupational Training Center in June and is now employed at a workshop for the handicapped. But he is still in temporary housing at Staten Island Developmental Center awaiting permanent placement in a group home.

His mother still cries at night, wondering what will happen to her son.

Anne Seery, an aide to state Assemblyman Robert Stranieri and an advocate for the DeLillos, is still frustrated in her attempts to resolve Joey's plight.

Joey's story was chronicled by the Advance in a three-part series published in April. The series told about Joey's disorder, Prader-Willi Syndrome, a rare dysfunction of the central nervous system which causes mental retardation, physical immaturity, emotional disturbances and an insatiable appetite.

Prader-Willi victims have a tendency toward gross obesity and problems like diabetes and heart disease. Their life expectancy is very short. People who have had experience with the syndrome say the only hope for Prader-Willi victims is to put them in a controlled environment which limits their access to food.

Joey's parents have spent several years trying to find such an environment for their son, but because of the unique problems posed by the syndrome, there are few options available.

Moreover, the state agencies involved — the state Office of Mental Retardation and Developmental Disabilities (OMRDD) and the Committee on the Handicapped, a division of the Board of Education — could not come to agreement on the proper place for Joey, and that prevented his placement in a special school for Prader-Willi



Joey DeLillo

victims. Now that Joey has passed his 21st birthday, he is too old to enter the school.

When the series was published in April, Joey had been living at SIDC's respite center for six months, although the center usually takes clients for a maximum of two weeks. This spring, officials said they were discussing where Joey was to go. One OMRDD official optimistically predicted that Joey would be in a group home by summer.

That hasn't happened. Joey is still at SIDC. His mother and Anne Seery say there has been no word on Joey's permanent placement for several months. "I just wrote a letter to (OMRDD Commissioner) Arthur Webb asking him what's going on," Ms. Seery said. "You really have to keep after them. I've been batted around from one person in the agency to another." Mrs. DeLillo says Joey is happy at SIDC. "They are very good to him," she said. "I really can't complain."

She would like to see Joey stay there, although that is not an option. The lack of other op-

tions worries her. "I still cry," she said. "I get so upset about this. I think about Joey constantly."