

Is system friend or foe to handicapped?

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Who is to blame for the plight of Joey DeLillo?

His mother blames the system. Her advocates also blame the attitude of state officials. State and local officials blame the shortage of resources for the handicapped and the lack of options.

But for some reason, it took Gloria DeLillo three years to move her 20-year-old son out of her home and into a residential placement which she says he so desperately needs. And even now, Joey's future is a question mark.

Joey, who turns 21 on April 4, has Prader-Willi Syndrome, a rare disorder which causes mental retardation, lack of physical development, behavior problems and an insatiable appetite which can lead to obesity and, in turn, diabetes, hypertension and heart trouble.

Since 1980, Mrs. DeLillo has been trying to move him from the Richmond Occupational Training Center (OTC) to a residential school in upstate New York specially geared for youngsters with Prader-Willi. Mrs. DeLillo and her advocates said the placement is necessary because neither she nor OTC could handle Joey's temper tantrums or monitor his uncontrollable eating.

But the placement has been blocked by the Board of Education's Committee on the Handicapped which said Joey's needs could be served on Staten Island.

After Mrs. DeLillo and her advocates made a desperate plea to the state Office of Mental Retardation and Developmental Disabilities, Joey was finally moved out of the DeLillo's home in November and placed in the respite center at Staten Island Developmental Center.

Five months later, Joey is still at Willowbrook, even through

the respite center is designed for short-term care only. Officials at OMRDD, which is now handling the case, have still not figured out a permanent solution for Joey.

Despite Mrs. DeLillo's difficulty in obtaining care for her son, state and local officials sidestep blame. Indeed, some officials say there is no blame associated with the case; that, in fact, the DeLillos have been served well by the system.

"We've done as much as we can do for him," says Thomas Dugan, chairman of the Committee for the Handicapped in District 31.

It was Dugan's office which refused to approve Joey's placement in a residential facility. Dugan says the decision in Joey's case was based on Joey's educational needs, which Dugan says were being met at OTC.

But what about Joey's other needs? The uncontrolled eating? The temper tantrums? The problems his parents experienced in handling the boy?

"Those are management issues, not educational issues," Dugan says. "We have to see if we can meet educational needs."

Dugan points to the results of an impartial hearing held in June 1983 on the DeLillo case. The hearing officer agreed with the Committee on the Handicapped that Joey belonged at OTC, although the officer acknowledged some reservations.

"Without question, Joseph would be better served in an institution specifically devoted to care of Prader-Willi patients," the hearing officer said in his written decision. "Current law, however, does not require the Board of Education to provide an optimum environment for special education students, but only a suitable and appropriate placement."

The hearing officer did criticize the Board of Education for

its continued ignorance about Joey's unique disabilities.

"It is unfortunate that the Committee on the Handicapped and school personnel were so poorly informed about Prader-Willi Syndrome throughout Joseph's stay at the Richmond Occupational Training Center," the hearing officer wrote. "Failure of the Committee on the Handicapped and its school personnel to independently attempt to learn something about Prader-Willi Syndrome must be condemned."

Dugan shrugs off philosophical discussion on whether the state has evaded its responsibility to the DeLillo family by ignoring all but Joey's educational needs.

"That gets into the whole question of the role of state government," he says. "I think all the due process rights in this case were fulfilled."

Officials from the Office of Mental Retardation and Developmental Disabilities, which entered the case in November when Joey was placed at Willowbrook, are more sensitive to the problems experienced by Joey's family, although they are also defensive about their agency's response to the case.

"We appreciate the problems suffered by the family," said Barbara Hawes, OMRDD associate commissioner for state-

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wide services. "But I should note that in this instance we were able to provide service when the need arose, and we're still working on the case."

Ms. Hawes acknowledged that Joey's present placement at the Willowbrook respite center is not ideal, and that he should be moved into permanent placement as soon as possible.

"But access to group homes is a difficult problem for everybody," she said. "There are not enough residential beds available for patients who need the service. We are opening beds as fast we can, but we can't open them as fast as people need them."

While everybody involved in the DeLillo case agrees that the shortage of residential beds is one barrier to Joey's permanent placement, advocates for the DeLillos perceive an additional barrier — the inaction of bureaucrats who are processing the case.

"Nobody wants to assume responsibility," said Jerry Teehan, member of the Staten Island Borough President's Commission on the Handicapped. "They want to pass the buck."

Teehan says the DeLillo case is symptomatic of the obstacles faced by parents in seeking service for handicapped children. "It takes a sophisticated, dynamic, intellectual and wise per-

son to know where to go for help," he says. "Most parents stumble around until someone notices them."

And once parents are put in touch with the right agencies, the families must live with decisions made by bureaucrats who may lack understanding of the family's situation, Teehan said.

"They decide for us and not with us. Rehabilitation is supposed to be an agreement between the client and the bureaucracy. Ideally, it's the setting of a goal," he says. "But more often than not, government agencies take a patriarchal attitude and just decide what they think is best."

Bureaucrats, not surprisingly, disagree.

"I don't see it in such conspiratorial terms," said William Combes, program coordinator for the state Commission on Quality of Care. "It's not so cut and dried."

"A lot of people need to be served and there are not a lot of places to serve them," he said. "And I don't think the system has too much flexibility — it's too strained."

Another issue is whether the service system for the handicapped has become too weighted and too complex, which unnecessarily slows down the decision-making process in situations like the DeLillos'.

Anne Seery, senior legislative aide to Assemblyman Robert Stranieri and one of the DeLillos' advocates, says she has been overwhelmed by the number of agencies and people associated with the DeLillo case.

"The red tape is a terrible problem," she said. "It's not the lack of concern, it's the sheer numbers which makes it so frustrating."

Ms. Hawes debates that point.

"I think in cases like the DeLillos', many people are working very hard to see that Joey has every opportunity," she said. "The officials are not working to make the process cumbersome."

Mary Jane Barnett, another OMRDD official working on the DeLillo case, said she does not see the DeLillos as victims of the system. "Mrs. DeLillo is not a victim," she said. "She is more a ship tossed around in the wind because of Joseph's problems."

But Teehan sees it differently.

"Damn right that kid's a victim of the system," he said. "And I don't believe this case is an exception. It may be in a minority, but it's not an exception."

"I'm not the only one," Mrs. DeLillo said. "There are a lot of kids who are just like Joey."

(This is part three of a series. Tomorrow: Other kids like Joey, and the problem called 'aging out'.)