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State-voluntary group home truce falling apart

By JULIE MACK

After Benny Panzella was diagnosed as mentally retarded, his parents vowed to keep him home for as long as possible. They wanted only the best for Benny, now 25 years old, and avoided any suggestion of placement at Willowbrook State School.

"I felt being at home was better for him," said Polly Panzella, Benny's mother. "I wanted to try to do whatever I could."

Her dismal appraisal of Willowbrook, now Staten Island Developmental Center (SIDC), was vindicated in the early 1970s when the institution was described as a "warehouse" for the retarded.

Yet, paradoxically, Polly Panzella now regrets that she never had her son institutionalized.

"I should have committed him, even for a month," she said. "Others in the same situation also look back now and say 'why didn't we.' When it finally occurred to us, SIDC was closed to new admissions."

A startling statement perhaps, but perfectly understandable in light of recent developments surrounding care of mentally retarded in New York State.

It all goes back to the Willowbrook Consent Decree, which promised dramatic reforms at Willowbrook and for its patients, giving those people first priority in a new system of care

for the mentally retarded.

To carry out these reforms, particularly the movement of clients from the institution into group homes, the state Office of Mental Retardation and Developmental Disabilities (OMRDD) asked the help of non-profit agencies, which had much more experience in working with the retarded in a community setting.

But the voluntary agencies had their own ax to grind. Most of those organizations were started by parents who rejected state institutions and created their own system of services. Disdainful about the state's past work in with the retarded and skeptical about proposals for the future, the "voluntaries" were also resentful that Willowbrook patients might be awarded special treatment.

So early on, the battle lines were drawn. Yet, the voluntaries agreed to help the state implement the reforms, primarily because they saw an opportunity to help their own people — the so-called community clients, who had never been institutionalized — in the process. A truce was formed: The state would build group homes to be operated by non-profit agencies, and each home would have a 50-50 split between class clients — past and present Willowbrook patients represented in the class-action lawsuits — and community clients.

Advocates for community clients still grumbled that they were being shortchanged. After all, community clients far outnumbered class clients — Staten Island's retarded population is estimated at more than 10,000 and only a few hundred of those people were in Willowbrook. But the developments of the 1970s were a promising beginning, and advocates of community clients were optimistic about the future; if nothing else, they were getting more attention from the state than they ever had in the past.

That optimism has been shattered in recent months by indications from the state OMRDD that this year's funding for group homes will be directed primarily toward class clients, to the exclusion of community clients.

Betsy Crowell, acting associate commissioner of the New York City County Services Group at OMRDD, said homes operated by voluntary agencies will continue to have a 50-50 split, but those homes run by state employees — and the trend is in that direction — will have, as a general rule, only class clients. It is a course that the state must pursue because it is under court order to move more than 750 patients out of Willowbrook by 1985, said Ms.

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Crowell.

Advocates for the community clients understand the logic, but they are also furious over the shift in emphasis.

"You get people who say they've done the good thing, the moral thing, by keeping their child home and they're asking why they should be punished when those who abandon their child to institutions are rewarded," said Assemblywoman Elizabeth Connelly.

"There is absolutely no argument that de-institutionalization must continue," said Genevieve Benoit, chairwoman of the Staten Island Council for Developmental Disabilities. "But we want parity. That's the entire issue."

"We understand the pressure caused by the court order. We understand the time limit. But we think that two things can be accomplished at the same time. We can achieve parity and a system of services that leaves everybody better off. But we're not seeing it happen."

Some argue that the state should continue to let non-profit agencies operate group homes. That would maintain the 50-50 split, the argument goes, and the state would benefit because voluntaries can provide better ser-

vice at a lower cost. That was confirmed by a report published last summer by the New York State Commission on Quality of Care for the Mentally Disabled.

Yet the OMRDD is also under pressure by the employees' unions who want to avoid layoffs resulting from de-institutionalization and strongly encourage the state to have homes staffed by state employees.

"The state has some legitimate labor problems — de-institutionalization costs jobs, so the instinct is to go with state-operated homes," said Marjory Ames, director of the InterAgency Council on Developmental Disabilities in Manhattan.

Others are more bitter.

"It bothers me that the state is pushing voluntaries aside," said Mrs. Panzella. "I've seen what the voluntaries can do. I don't trust the state to take care of my son, and I think that's how most parents feel."

The realities of the situation have also inspired thought among some parents to place their retarded children in state care, if only temporarily, to ensure their priority in future distribution of services.

"Apparently, there is no law or legal precedent that entitles people to services automatically. There is no way to force the state to do anything for community clients," said Ms. Benoit. Yet, once a person is institutionalized, placed in a group home or put in

foster care, the state must assume some responsibility for that person's future.

"If you were a parent and aware that a mentally retarded child had no rights to service as an adult unless he or she was institutionalized in the system, what would you do?" said Ms. Ames. "We're not saying the state is forcing parents, but they sure are encouraging people to put mentally retarded children into state care to insure that they get services down the line."

"Many families like to keep their kids at home. But they know that if they do, it's with minimal help from the state. It's an awful thing to force on people."

State officials acknowledge the conflict, yet they say it is unavoidable. The state simply does not have the money or the ability to immediately institute a complete network of services for everybody.

"I understand what parents are saying, and we are sensitive to that. It's an awfully emotional issue," said Midge McGraw, spokeswoman for OMRDD. "I agree that more support services are needed for community clients, and I agree there is a need for more residential beds."

"I don't think advocates and parents want anything more than what state officials want. We are working toward the same ends. It's just a question of time."

(This is the third article in a six-part series.)