

Group home dilemma leaves many

frustrated

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Whenever administrators decide to move him to a new room at the Brooklyn Developmental Center, Richard Montuori becomes frustrated and bangs his head against the wall.

It could be worse, and at one time it was. As a young boy, Richard, who is mentally retarded, spent a year in the former Willowbrook State School just before it was revealed in a series of articles by the Advance in the early 1970s that hundreds of retarded children there were being warehoused, neglected and treated little better than animals.

After its closing more than a decade later, the state of New York promised Richard's parents, Carmine and Mary, that their son would be able to live in a group home — an ordinary house in an ordinary neighborhood with nearly one-to-one care.

"He was 13 at the time (he left Willowbrook). He's 33 today and he's still in an institution," said Montuori, who lives with his wife in Sheepshead Bay, Brooklyn.

Group homes are seen as a humane and progressive solution by many who care for the mentally retarded. But difficulties in opening a group home have complicated efforts to place people like Richard.

There are more than 800 mentally retarded people either in a group home, care program or institution on Staten Island, or who are seeking placement here. Countless others live at home, sometimes seeking outside services.

Most of the former residents of Willowbrook, officially renamed the Staten Island Developmental Center, have been placed in group homes. Other patients, like Richard, are still in institutions, awaiting placement. And 84 residents are still on the grounds of the former facility, without a stable home.

Because they have two grown children living on Staten Island, the Montuoris were delighted to hear several months ago that Richard's name had finally been added to the waiting list for a group home here. When the parents are no longer able, Richard's siblings can visit him in his new home.

More than anything else, Richard needs a place where he can get consistent, personalized care.

Regulations delay homes

New York State says it has taken so long to set up and fill group homes because of tight regulations, designed to ensure safe environments and prevent throwbacks to the days of Willowbrook. The homes typically have 8 to 10 residents.

Parents of retarded children have their own ideas



ADVANCE PHOTO/MIKE FALCO

Vincent and Annette Rooney and their son James, who must wear a helmet to protect his head from injury when he has a seizure.

about the delays.

"I think the biggest problem is the support from the community," said Mrs. Montuori. "People do have to be educated about the way these people are."

Mrs. Montuori was referring to a chronic fear of group homes among potential neighbors. Whenever a new site is announced, often at a community board meeting, invariably the battle cry goes up. Although the resulting controversy rarely delays a siting for long, the state must take a community's opposition into account.

"It complicates the process," said Barbara Schubert, information exchange coordinator for the Staten Island Developmental Disabilities Office (DDSO).

"They'll never get rid of institutions unless people get rid of this (fear)," Montuori said. Residents of neighborhoods that protest the placement of group homes nearby cite the horrors of Willowbrook to justify their fear, instead of realizing those horrors are exactly why group homes are so necessary, he said. "People have forgotten about that now."

It's like "doing the same thing in another way," Mrs. Montuori said.

The frustration of waiting so long for a placement for Richard has built upon itself, reaching the point where Mrs. Montuori now blames herself for not fighting hard enough to get done what is actually the job of the state.

"Maybe things will start moving now that I'm mad," she said.

She is not alone. There are about 170 names on the waiting list for group homes in the borough.

Although that number is not tremendous, a particular situation may force a family into what experts call a "crisis situation."

Earlier this year, 19-year-old James Rooney unexplainably began having seizures. The seizures last only four seconds, but can be dangerous. When James gets them, he freezes like he has gotten an electrical shock. As a result, since February, James has fallen twice, once through a coffee table and then into his bedroom door. The bolt in the door's lock caught his head in just the wrong way and he had to get stitches.

The boy now wears a bicycle helmet around the house — every minute of the day except when he sleeps. His parents put an electric mat on the floor next to his bed so an alarm warns them if he gets up at night.

More than anything else, James needs round-the-clock supervision. If he is alone for a minute, his life is in danger.

About 70 of the individuals waiting for a place in a group home, like James, need a place immediately.

In recent weeks, James has been denied placement at three group homes because of his seizures. But the search goes on, and his parents, although their voices bear a note of resignation, say they keep hoping.

For Richard and James, the problems are somewhat different. But the solution is the same: placement in a group home.

Neighborhood resistance

The neighborhood resistance to group homes comes into sharp focus at community board meetings, where group home operators seek public input on the siting of facilities. Opponents come up with a surprising range of arguments against the sitings: property values of surrounding houses will fall, the retarded residents will wander the streets hurting children or they may even hurt themselves if the area lacks adequate safeguards or contains potential dangers like empty swimming pools.

By state law, group homes have to follow rigorous standards in testing sites for safety hazards.

But the opposition goes on, and underneath it, the fears persist. This year alone, communities have protested proposed group home sites on Rockland Avenue, South Greenleaf Avenue in Westerleigh, Galloway Avenue in Port Richmond and Selkirk Street in Rossville. The Rossville site, planned by Staten Island Aid Inc., one of several group home operators in the borough, was recently approved by the state despite community objections.

And last October, about 200 Fort Wadsworth residents appeared at a Community Board 1 meeting to oppose a facility for 11 adults on Hope Avenue.

A 1988 state report on the prospects of closing New York's institutions barely mentioned community opposition, excluding it from what the study called the "challenges and tensions" of the plan.

Some say the problem eventually solves itself; that after neighbors have spent time with the residents of a group home in their community, they become accustomed to the new addition.

In 1979, Bernard Kosinski adamantly opposed a new group home on Cromwell Avenue in Dongan Hills for eight severely retarded individuals. He and his neighbors even took the state to court, but lost. Among other things, they feared dangers to their children and sliding property values.

"That never happened," he said recently, regretting his original stance. "They're harmless as far as I'm concerned."

The Cromwell Avenue home was among the first of a handful established in the wake of the Willowbrook revelations.

Today, Kosinski, a vice chairman of Community Board 2, watches other neighborhoods rise up in protest the same way.

"No community should be exposed to oversaturation of the group homes," he said. But, he added, no community should reject one because they worry it will detract from the neighborhood. "They (the retarded) have to live someplace. That's how I feel about it."

State focus shifted

Although the state has made headway, much remains to be done.

The dismantling of the troubled Willowbrook complex not only ended hellish conditions for its patients, but helped to shift the focus of the state's approach to treatment. Calling for the eventual transfer of all of Willowbrook's residents to smaller group homes, a 1975 agreement between the courts and the state government set in motion a race against time to provide beds in smaller, more ordinary environments where patients could get more personal attention.

Gov. Mario Cuomo announced in 1984 — a year after a legal dispute concluded that the state should renovate and greatly reduce the size of Willowbrook — that he would instead close the center, thus speeding the transfer of patients to neighborhood settings.

His goal seems to be approaching slowly but steadily.

"We need a lot of development on Staten Island," said Dr. Gerald Spielman, a former chairman of the Staten Island Retardation and Disabilities Council and the director of the Elizabeth W. Pouch Center for Special Children. Care facilities are lacking, and new projects proceed at a slow pace, he said. More than just acquiring beds, Spielman said, the community needs an even, progressive effort to increase facilities and programs.

The process is slow because of the state's stringent regulations, in place to ensure the quality of the homes.

"It's very time-consuming," said Jane Maguire, the council's current chairwoman and the director of residential services for Volunteers of America. "It takes a lot of work on everybody's part."

"It's frustrating when you're going through the process, but I can understand the need for it," she said. With effort, "Maybe there could be a way of speeding up the process."

For information about the group home placement waiting list and other services, call Ms. Schubert in the Staten Island DDSO at 351-7701.