

Homes for the retarded provide only one answer

By JULIE MACK
To see them now, it is hard to believe that Tom and Mary spent most of their lives in institutions for the mentally retarded.

Released in the aftermath of the Willowbrook consent decree, they are married, live independently in their own apartment on Staten Island and are raising a son. They still utilize support services, but they function well enough to cope with life's daily tasks on their own.

They have made it. Their story (the names have been changed) is an example of the wonders of deinstitutionalization. Indeed, the movement of the mentally retarded from institutions to the community is generally considered one of the most dramatic and rewarding developments of the consent decree — the state's agreement to reform services in the aftermath of the scandals at the Staten Island Developmental Center, then called Willowbrook State School.

But the movement to community living has not been without problems: The state Office of Mental Retardation and Developmental Disabilities (OMRDD) has had to face neighborhood resistance, controversy over size of

community residences and complaints that not enough homes are available.

In some respects, the situation has improved in the past decade. Community opposition to group homes has abated in recent years. OMRDD and the non-profit agencies which operate group homes have become more sophisticated in their attempts to win the approval of neighbors, and the public has become more understanding and tolerant.

"The community acceptance issue is a problem we're overcoming, although we still got a long way to go," said Joel Levy, executive director of the Young Adults Institute, an non-profit agency for the retarded in Manhattan.

"Whenever a person is moved into a community home and it works out, it becomes a positive advertisement," Levy said. "The homes become more accepted as the public starts to have a frame of reference and they see it works in other areas."

A study by the New York State Institute for Basic Research in Mental Retardation shows that a community's resistance to group homes usually fades once its fears are not realized.

"Once the home becomes es-

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established, it is usually accepted or ignored," said Robert Lubin, a scientist at the Institute for Basic Research.

But while deinstitutionalization is running smoothly in some respects, it is becoming more difficult in others.

A major issue now is that those who remain in the institutions are the more severely handicapped patients. Most are severely or profoundly handicapped; many also have physical disabilities. Some need constant medical attention. Others have emotional problems and are psychotic as well as retarded.

"We don't have those beautiful, bright children here anymore," said one employee at Staten Island Developmental Center, noting that the patients in at least one building at the SIDC has a propensity for violence. "You say you want more out of here. OK, that's all well and good. But where are you going to get the

staff and facilities to care for these clients?"

Indeed, the question now facing state officials is where to go from here in the deinstitutionalization process.

The debate is now centering on the size of community residences. The state is currently restricted by the consent decree to a maximum of 10 beds in some homes and 15 beds in others, depending on the type of residents.

The state agency for the retarded is suggesting that severely handicapped patients could be better served in facilities with as many as 50 beds. Officials claim such residences could better serve those patients who need specialized medical care.

Moreover, say state officials, such homes would hasten the movement of patients out of the institutions, because it is difficult to find smaller homes and apartments in New York City that fit the needs of multi-handicapped

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patients.

"I don't think the quality of care would drop in the larger facilities," said Midge McGraw, a spokeswoman for OMRDD. "In fact, the quality of care could be better because of more specialized staff we would supply, like around-the-clock nursing."

But the idea has not set well with some parents and professionals, who argue that larger homes would be nothing more than small institutions.

Staten Island already has one such facility, the Nina Eaton Center operated by United Cerebral Palsy of New York State, and even the UCP people say it is nothing like a group home.

"Fifty people under one roof is great for summer camp, but you wouldn't want to spend the rest of your life in that setting," said Keith Penman, regional director of the non-profit agency.

Penman ticks off the advantages of a 10-bed home compared to a 50-bed facility: Closer camaraderie between patients and staff, more privacy, and greater capability for patients to "manipulate their environment" because there are fewer restrictions.

These are differences that that enhance the personal growth of even severely and profoundly retarded, multi-handicapped persons, Penman says.

Proclaiming that smaller is better, plaintiffs involved in the original consent decree are not only fighting the idea of 50-bed facilities, they also are lobbying for more three-bed homes.

The fight over numbers was dragged into federal court last spring, and state officials asked to have the consent decree altered to allow for larger residential facilities.

Judge John R. Bartels denied the request, but an appellate court recently sent the case back to Bartels, claiming that the judge had not taken into account the state's expert witnesses.

Bartels has not yet issued a new ruling, and probably will not in the immediate future, because the plaintiffs are now asking the U.S. Supreme Court to hear the case.

Participants in the debate agree it is a sticky situation, and note that each side is motivated by more than just finding the best

care for patients: The state wants larger facilities because they are more cost-efficient and would hasten the deinstitutionalization process; some parents, on the other hand, may be inspired by guilt.

"The idea of the three-bed apartments caters more to the needs of parents than to clients," said Tony Pinto, president of the Benevolent Society for Retarded Children. "The three-bed apartment makes me feel better, but is the client that much better off? For the situation that exists today, 50-bed facilities could meet the needs of some."

"In this day and age, cost-effectiveness is certainly an issue," said Ms. McGraw, OMRDD's spokeswoman. "We have to have good quality care. We have to deliver the services. But money is tight and we have to be cost-effective."

The current controversies are also overshadowed by the larger question of whether total deinstitutionalization will ever occur.

Some of the more idealistic advocates say that everybody could benefit from community living. Others are more pessimistic.

"We're not naive enough to believe that everyone fits in a group home," said Ms. McGraw.

"Not everyone can be deinstitutionalized, although that's purely a personal opinion," said Marjory Ames, of the Interagency Council on Developmental Disabilities in Manhattan. "A small percentage will always need to be in the institutions — the elderly, those who are both mentally retarded and mentally ill.

"The problem is that you can't let the pendulum swing so far in favor of deinstitutionalization that you ignore needs of some of the population."

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