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Bed shortage widens

institution-community rift

The shortage of community beds is one of the biggest problems facing New York State's mentally retarded population, agree state officials, parents and advocates.

A spokeswoman for the state's Office of Mental Retardation and Developmental Disabilities said her agency estimated that the shortage of residential beds, both in the community and in institutions, will reach 9,000 by 1991.

The decrease in institutional beds is to be expected, as the state continues its movement of patients into community residences. But the state is not establishing group homes and supervised apartments fast enough to meet demand.

Staten Island presently has 38 group homes and supervised apartments, each serving three to 10 clients, and housing a total of 166 people.

Yet, more than 200 people here are currently awaiting placement.

That includes about 100 patients at Staten Island Developmental Center and the Karl Warner Center, who have Staten Island listed as their "borough of origin" and should be placed in this community if and when they leave the institution. Another 200

on the Willowbrook campus who are orphaned or abandoned and have no borough-of-origin could also be placed here.

Of even more significance is the demand for placements from families of community clients who have never been institutionalized. The Island's Borough Developmental Services Office has a waiting list of 100, a number expected to increase.

While many families prefer to keep a retarded child or adult at home, there are times when that is no longer possible — when parents become old or die; in times of family crisis like divorce or illness; when a patient needs more specialized care — and an alternate living situation is necessary.

In the past, such patients were placed in an institution; now the state considers that only as a last resort. Thus, the shortage of community beds is particularly acute.

"This morning I dealt with an 85-year-old mother who has had a heart attack and cannot care for her 60-year-old daughter. But there are no openings," said Joel Levy of the Young Adult Institute in Manhattan.

Marjory Ames, of the Inter-agency Council for Developmen-

tal Disabilities in Manhattan, said she knows of one agency that has a waiting list of over 1,000 community clients with a median age of 42 who need placement in community residences.

"You have to think of the implications of this," said Ms. Ames. "These people have been taken care of by their families for more than 40 years with minimal or no help from the state. The parents are in their 60s, they could die at any time and they are scared. All the agencies can say to them is: 'Just don't die right now.'"

The situation is complicated by the Willowbrook consent decree, the 1975 agreement by state officials to improve care for patients at Willowbrook State School, since renamed Staten Island Developmental Center. A major aspect of that agreement is the movement of patients from the institution into the community.

Because of the agreement, the state must move more than 750 patients out of Willowbrook by 1985. As a result, Willowbrook patients are receiving priority placement as new group homes open. Not surprisingly, that angers advocates of community clients.

The obvious solution, of course, is to establish enough group

homes to meet the current demand. But that is easier said than done.

"We have clients that are ready to be placed, but we don't have enough community sites," said James Walsh, acting director of the Staten Island Developmental Center. "The site selection process is complicated; you have to go through a lot of red tape and community opposition."

The state is further handicapped by New York City's housing shortage and the lack of homes suitable for use by multihandicapped clients.

The state has allocated \$12.6 million for capital expenses to establish new group homes this year. "We certainly plan to have a more ambitious development program in New York City in the next two years compared to the past couple years," said Betsy Crowell, acting associate commissioner of the state's New York City County Service Group. But, she added, "That is tied specifically to the Willowbrook run-down."

Moreover, a budget of \$12.6 million for the entire state is not all that generous considering that a new home opened this summer in Oakwood cost almost \$500,000,

said Keith Penman of United Cerebral Palsy of New York State.

The number of beds allocated for community clients isn't the only gripe. Advocates of community clients also complain that state-operated residences are planned around the needs of patients in institutions rather than those in the community.

Both Ms. Ames and Levy said that the current trend in community residences is toward facilities for the multihandicapped and more severely retarded patients, because those are the people mostly likely to be institutionalized. "That means almost 100 percent of the new residences are for less than 10 percent of the mentally retarded population," said Levy.

"There are no matches in the community for the clients left in Willowbrook," added Cora Hoffman of United Cerebral Palsy of New York State. "The ones left in the institution are very, very low-functioning or multi-handicapped."

But the state officials say they have few options but to emphasize placement of Willowbrook patients.

"We wouldn't have the complaints if we structured the residences around the needs of the

community clients, but it's not realistic at this point," said John Lamendella, administrator of the Borough Developmental Services Office. "We have the consent decree and we have to deal with that. The OMRDD is under some difficult time constraints."

But even if this was not a mandated matter, Walsh argued that the state has the correct priorities.

"We have limited resources, and we have to look at how we can best use those resources," he said. "If I have one bed and two clients, one that's profoundly retarded and multihandicapped and another that is mildly retarded, which am I going to serve, especially when I can maintain the second person at home with support services?"

Despite the problems, said Walsh and Lamendella, advocates of community clients should not lose hope that their needs will remain unfulfilled. The administrators provide assurances that the establishment of group homes will continue even after the institutions have been emptied.

"It's an ongoing process," said Lamendella. "There's a need for patience."

— JULIE MACK

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