

# For a few, life after

By CHRISTOPHER RINGWALD  
ADVANCE SPECIAL WRITER

The spirit of the Willowbrook Consent Decree is that people should live as much as possible as if they were not mentally retarded. Few former Willowbrook residents do, but Melita Diaz comes closer than most.

In 1954, a judge gave Diaz' mother the choice of Willowbrook or an upstate facility as homes for six of her 12 children who were handicapped. At the age of 5, Diaz was classified as mentally retarded and entered Willowbrook.

After a quarter of a century in Buildings 2, 21 and then 33, Diaz was placed with a foster family in 1979. Later she found one apartment by herself and then her current one in a housing project under the shadow of the Gowanus Expressway. She lives with her 5-year-old daughter by a former boy friend.

Sitting at a plastic-topped table in her clean, cramped apartment, Diaz remembers a life at Willowbrook degenerating. Her well-behaved, bright little girl climbs into her lap.

"When we were little it was nice there, we would go out and go to Willowbrook Park and feed the ducks," she said. "Sometimes (the staff) would take us to the forest to pick blackberries.

"But after 1960 it began to go downhill and it got crowded in 1965, 1967. The staff started to hit me in 1972. I hit back so they gave me drugs because of my attitude problem.

"They would hit us with baseball bats and pipes and call us 'retarded b-----'. It makes you feel terrible to be called that, like you're not worth anything."

Diaz took a radical approach to get out of Willowbrook. Denied her first request for release, she deliberately ate less and lost 56 pounds until she weighed 102. Alarmed, the staff approved her transfer but with little encouragement.

"One employee told me 'you'll be back within a year.' But, no, I spent 25 years there and that was enough."

Diaz' progress is followed by the Consumer Advisory Board. Anne Thompson of that office credits Diaz' drive for her independence and respects Diaz' devotion to her daughter.

Diaz is not angry about being



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put away and remembers bi-weekly visits from her mother who faithfully brought a cooked turkey to her children every Thanksgiving.

At the same time, Diaz remembers that upon her release, "I said that if ever have a child that I would never do that with them no matter what." She strokes her daughter's hair.

"All the things I didn't have, I want for her."

When first out of Willowbrook, Diaz worked as a clerk for the Consumer Advisory Board. Bad experiences with baby sitters keeps her home now to watch her daughter. She applied for and receives public assistance on her own.

"I have a social worker but I'm not in touch with her; I'm doing fine on my own." Thompson calls and occasionally visits. Diaz manages. Each month, she stretches a combined \$282 in food stamps and welfare to cover her \$117 rent, food and other costs. Diaz wants to work again, maybe when her

daughter can fend for herself in the kitchen and on the street.

"I would like to go back to school to learn more how to read better and do times tables. I could do office work, that's what I did before. I could go to school in the nights and work part-time in the mornings."

Diaz lives as normally as possible. She knows her neighbors; she supplements her daughter's education with extra math and spelling lessons over the kitchen table; she shops and cooks; her relatives annoy and delight her. One sister crowded in with four children to stay for several weeks recently.

Several friends from Willowbrook live in group homes. Diaz visits but doesn't envy them.

"They should be teaching those people how to cook and letting them be adults," she said, and explained her creed. "The good Lord watches over me. And I don't open the door to any strangers.

"At Willowbrook, they told me that it would be very scary, that I couldn't make it out in the world

Willowbrook is quite normal

alone. But I was a child that way and I wanted to find out."

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Melita Diaz is one of approximately 200 former Willowbrook patients who live on their own. The majority live in isolated pockets of the mentally retarded world, some in group homes or with surrogate families, others in institutions. For many, there is little movement "from dependent to independent" living.

Rita Martin's Consumer Advisory Board monitors treatment of 800 of the original 5,400 Willowbrook clients, and she is critical of state compliance with the Willowbrook judgment.

"Four of our clients are living independently," she said recently in her office on the almost deserted Willowbrook grounds.

"The 100 who are living in the developmental centers (large facilities providing extra services for hundreds of residents) are not living in 'the most normal living conditions possible.' The centers are far too restrictive." By the state's estimate, more than 2,600 are in community placements — group homes, with surrogate families, or in supervised apartments.

As for those clients living in homes such as Seigel's and Weiner's, Rita Martin may not be monitoring the Willowbrook class when it is back in the community as far as possible. Both her office and the other monitor, the Special Master, will be terminated in 1992 if the state can certify that all class members have been placed in "community or qualifying facilities."

Staffs at both offices expect to be out of work then. "Community and qualifying facilities" have become elastic terms.

A 1983 Federal Appeals Court decision allowed placement of clients in facilities with up to 50 beds. Reformers are alarmed. Carabello called the larger facilities a "disgrace" and said, "the state's copping out."

The state now classifies units with up to 30 beds as community residences. "Not everyone who works for the state is happy with that," said Ellen Ashton of the state Office of Mental Retardation/Developmental Disabilities (OMRDD). The Special Master's Office wants a 14-bed limit.

Many group homes now are categorized as Intermediate Care Facilities in order to qualify for Medicare payments. These facilities can have more than 16 beds, which runs against the spirit of community placement. The trend toward larger facilities is widespread.

"They're even opening up nursing homes for mentally handicapped patients with 30 beds," exclaimed Massarelli.

"In Massachusetts, they're rebuilding many of the state schools for mentally retarded people. Reinstitutionalization is happening, it's not just a possibility."

Rita Martin agreed. "In New York, both the Department of Mental Health and the Office of Mental Retardation are regressing to the use of larger facilities."

"There is some movement to the 30-bed facilities upstate," Ms. Ashton said. "But there is substantial compliance with the primary standards of care." There are, she said, limitations — some budgetary, some attitudinal — to the normalization process.

"The waiting list for the developmental centers here has hundreds," she said. "Every client is ready for community placement, but the community is not ready to provide the sort of care they need. Occupational and physical therapist positions are very hard to fill. Property for residences is expensive, especially in the five boroughs. And there is plenty of resistance.

"Four homes under construction or renovation were torched," Ms. Ashton said, "in Queens in 1987, Northport in 1982, Shirley Mastic in 1980 and Huntington in 1978."

"It requires a real commitment on the part of people that the clients should be living as normally as possible," said Rita Martin. "It takes a lot of energy." She recalled one supervisor who would sleep on the couch in new group homes for the first few weeks to see how they were working out.

The energy will have to come from ordinary citizens and not just caseworkers. Only neighbors can make a person feel he or she is important to a community by being their friend.

The task is formidable, given the weight of society's devaluation of the handicapped and the conversion, by the handicapped, of society's prejudice into a negative self-image. Massarelli told of a deaf man who was mentally retarded and sat in his room for hours speaking in sign language to himself.

"What's he saying to himself?" she asked the man's caseworker.

"I hate you," was the answer.

"The Willowbrook reforms bring us to the point where we have to change the character of our communities," Kendrick said. "We have been so preoccupied with the technical feats of deinstitutionalization, and people are so astounded to see that the handicapped can live in the community, that we have stopped learning.

"We see the handicapped as government's problem, and the Willowbrook reforms have simply changed the face of government. Instead of Willowbrook on Staten Island, we see smaller institutions on our street." Kendrick said it is the average citizen's turn to help.

"Just little things, like having a mentally handicapped person over for dinner — including them in our lives — is what's needed to show that it can be done." He, Massarelli, Cohen, Rita Martin, Grinnell and Thompson all entertain and visit former clients on their own time.

"The mentally retarded have changed and adapted because of deinstitutionalization but we haven't," he said. "And now it us as a community who have something to gain from them."

(This is the fourth in a series of five articles. Tomorrow: Willowbrook's oldest client.)

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