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# Willowbrook numbers down, problems remain

By JULIE MACK

It is not utopia, say state officials, but it is no longer hell.

Indeed, the Staten Island Developmental Center has changed more than its name in the past decade. Ten years ago, when the institution was still called Willowbrook State School, the center was routinely used as an example of the worst in care for the mentally retarded.

Care at the institution has improved tremendously in the past decade. It had to. The state's hand was forced by a class action lawsuit filed by parents of Willowbrook clients, a lawsuit which culminated in the Willowbrook Consent Decree in 1975. The agreement ordered reforms in almost every aspect of care at the institution, including clothing, recreation, patient-staff

ratio, programming and evaluation, education, food and medical services.

The biggest impact of the agreement was the reduction of the institution's population, which totaled at one time more than 6,000, through placements in the other institutions and supervised residences in the community. Presently, more than 1,000 clients are still on the Willowbrook campus, including 300 who are under the care of United Cerebral Palsy of New York State.

The smaller population, the improved patient-staff ratio and the establishment of daily therapy for residents are reasons for hope that the institution has upgraded its quality of life for residents.

"I just don't know if you can

even compare the institution now to what it once was," said James Walsh, SIDC acting director. "For example, in the mid-1970s there were 5,200 patients served by a staff of 1,800. We still have 1,800 on staff, but the patient numbers have dropped to 740.

"I think client services have improved tremendously. We're doing everything in our power not only to fill the letter of the consent decree but also the spirit."

Yet there is still cause for concern, according to some who claim the consent decree has never been fully and effectively implemented.

"The state has been well-intentioned, but the concepts have never been followed through and

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the central issues remain unaddressed," said Anthony Pinto, president of the Benevolent Society for Retarded Children, an organization representing past and present SIDC residents.

A basic issue is the lack of long-range planning, said Pinto, who notes that SIDC has had 11 directors and acting directors since 1975.

"There is no continuity, no commitment over a long time period," he said. Problems are handled when they become a crisis, rather than anticipating and defusing situations before they cause headaches, Pinto charged.

"An indication of how the 1975 plan has never been made truly effective is the fact that to this day, the state has not yet decided who will be among the 250 who will remain at Willowbrook," said Pinto. "In 1980 they promised to give us a list to identify that population which would stay here, and that hasn't been done yet."

Charges that the state's actions have been inadequate were bolstered in a court case last spring initiated by the plaintiffs in the

original lawsuit, who claimed that the state was violating the 1975 consent decree. Federal Judge John R. Bartels agreed with the plaintiffs, scolded the state for neglecting its responsibilities and ordered a special master to oversee SIDC's continuing reform.

Perhaps the most blatant violation of the consent decree has been the state's failure to depopulate the institution as fast as agreed. SIDC was to have only 250 patients by April 1981, but when the deadline arrived, the institution still had more than five times that number. The deadline now has been moved to 1985.

But the patient census is only one of many signs of how the state has been lagging, critics say.

"The state has spent a lot of time complying with one issue — placement," said Theresa Rafferty, head of the SIDC Consumer Advisory Board. "But that is only one aspect of the consent decree and there are deficiencies in other areas."

She claims that there are still people who are without proper therapy and treatment for medi-

cal and emotional problems.

"You can't believe how incomplete the records are," said Pinto. "We had one man who had been assigned the goal of learning to brush his teeth, only he had no teeth. We had a woman who was to be taught feminine hygiene, only she no longer menstruated. The records in no way relate to the needs of the clients."

Sometimes records are incomplete because of a chronic shortage of professional staff and the resulting cynicism of those who must develop care plans for individual clients, said Ms. Rafferty.

"They don't write down the real problems because staff has gotten used to the idea that no

one is going to address those problems," Ms. Rafferty said. "Why should they write down that Johnny Jones needs a speech therapist when there's no chance that the speech therapists can fit Johnny Jones into their schedule?"

"So staff develops a plan on what they think they can realistically get. Like anybody else, they get tired of making requests that are not fulfilled. But it gets to a point where the administrators don't know what is needed.

"For instance, we think that 70 to 80 percent of the center's current population is on psychoactive drugs. That indicates to us the need for so many behavior psychologists. I saw one report,

and I don't know whether it's true or not, but this report indicated a need for 60 psychologists and they don't have anywhere near that number.

"On paper it looks like they are staffed and overstaffed. But there is not enough attempt to deal with individual needs."

Walsh acknowledges that there are shortages in certain areas of staffing, particularly physical therapists, but he maintains that the majority of clients are receiving needed treatment. Those who are not, he said, are isolated cases.

Moreover, said Walsh, part of the problem is that the very structure of the institution, of any

institution, hinders patient growth.

"That's why my biggest goal is to continue the movement of patients out of SIDC," Walsh added.

But as long as patients remain in the institution, the quality of life remains an issue.

"It's hard to pose solutions in simple terms," said Pinto. "There's a lot of wasted funds. There's also a need to develop a new, more realistic time frame so that expectations are made into realities.

"The state needs to decide what its commitment really is," he said. "We have to maintain pressure."

(This is the second in a series of articles.)

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