

Willowbrook:

How does it serve today?

By JULIE MACK
A decade after the Willowbrook scandals, the state's care of the mentally retarded is undergoing a dramatic evolution, but the success are pockmarked by disappointments.

"The dream remains unfulfilled," as one parent of a mentally retarded client put it.

Reforms were pledged by the state eight years ago, in the wake of charges of inferior care for thousands of clients housed at the former Willowbrook State School.

The facility has since been renamed the Staten Island Developmental Center, the clientele has been spread among many facilities, and most parents and professionals readily acknowledge that treatment of the mentally disabled has improved in the last decade.

Yet many claim that not enough has been accomplished, particularly within the past few years. There is genuine concern that the state government is stagnating or even renegeing on its promises.

"I think the state has withdrawn its commitment to deinstitutionalization, to put it politely," said Keit Penman, regional director of United Cerebral Palsy of New York State, a

non-profit group contracted by the state to provide services for the retarded.

Among the specific complaints:

- Frustration from those who feel that the quality of care is still deficient at state-run institutions.
- Concern about the shortage of supervised community residences for the retarded.
- Bitterness among parents of retarded children who were never institutionalized and who claim their children are being short-changed in the present distribution of services.

The problems now facing state officials are an outgrowth of the Willowbrook Consent Decree, signed by then Gov. Hugh Carey in 1975 as settlement of a class action lawsuit representing Willowbrook patients.

Major reforms were promised on all aspects of care — therapy, clothing, medical care, patient-staff ratio. The biggest effect of the consent decree was moving people out of the institution and into community residences.

While the consent decree covered only Willowbrook patients, it inspired hope that the state would overhaul its entire service system for all the mentally retarded. In fact, the state has

worked closely with voluntary agencies to create a new network of support services.

Yet the new system is experiencing growing pains, and old issues refuse to go away.

It doesn't help that the mentally retarded population, and its advocates are factionalized, with sharp divisions between "class clients" represented in the Willowbrook Consent Decree and community clients who have always lived at home. Each client group has its own set of problems, its own priorities.

SIDC remains at the forefront of controversy, fueled by concern that the state is not fulfilling the

1975 agreement. Indeed, the state has already violated one of the main tenets of the original agreement, which was to reduce the institution's population (which numbered more than 6,000 in the early 1970s) to 250 by April 1981. A new deadline has been set for 1985. Meanwhile, more than a 1,000 clients still remain on campus.

Moreover, advocates for Willowbrook patients say they are still getting inferior care.

"The quality of life in institutions, including the cleaned-up Willowbrook, is still lower than

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that for a human being," said Murray Schneps, whose child was a patient at the facility.

That is denied by state officials, who claim that patient care at SIDC has improved tremendously in the last decade.

"It's not utopia, but it's better," said Midge McGraw, spokeswoman at the state Office of Mental Retardation and Developmental Disabilities. "The patients are well-fed, clothed. They live in cheerier surroundings in wards that are not overcrowded."

There are other issues. At the same time advocates of the Willowbrook clients say their people are not receiving enough care, others are claiming that past and present Willowbrook patients are receiving preferential placement in group homes.

This perception is particularly keen among parents of community clients who have never been institutionalized. These parents claim they handled their problems alone for many years, and now when they ask for relief from the state, they say they are being ignored in favor of those who abdicated their responsibilities long ago.

"These parents (of community clients) are furious," said Genevieve Benoit, executive director of the Staten Island Regional Retardation and Disabilities Council. "They are behind bitterness and into rage. They can't understand why their kids continue to be shortchanged."

While voluntary agencies have been working with the state to establish group homes, both sides are struggling over who should be placed in the homes.

The state is under mandate to move people out of institutions; the voluntary groups champion the cause of community clients. There is an "us-against-them" mentality at work here, and to some extent, it has led to a breakdown in communication between the state and some of the people it serves.

That particular situation is improving, said John Lamendella, administrator of the Staten Island Boro Developmental Services Office, but he does not deny that tensions exist.

"Voluntary agencies served the community population for many, many years, and the consent decree — good or bad — really addresses the needs of the Willowbrook clients," said



A scene at Willowbrook in 1975, when beds were crammed three inches apart into wards. Conditions have improved dramatically since then.

Lamendella. "There are limited beds and everybody has their own priorities and different commitments."

The situation has been exacerbated by the recent economic recession which has put pressures on the state's budget.

"People have to realize that not enough resources exist to achieve the level of idealism expressed in the original consent judgement," said Anthony Pinto, president of the Benevolent Society for Retarded Children. "They shouldn't abandon their goals — those goals should always be maintained — but they need to accept the realities."

"Parents also have to realize that there are other needs in society, other kinds of social programs drawing on the state's resources. The question is whether we provide paradise for a few at a cost of purgatory for the others."

While others may not want to

back away from the original goals, there is agreement that the situation is at a crossroads.

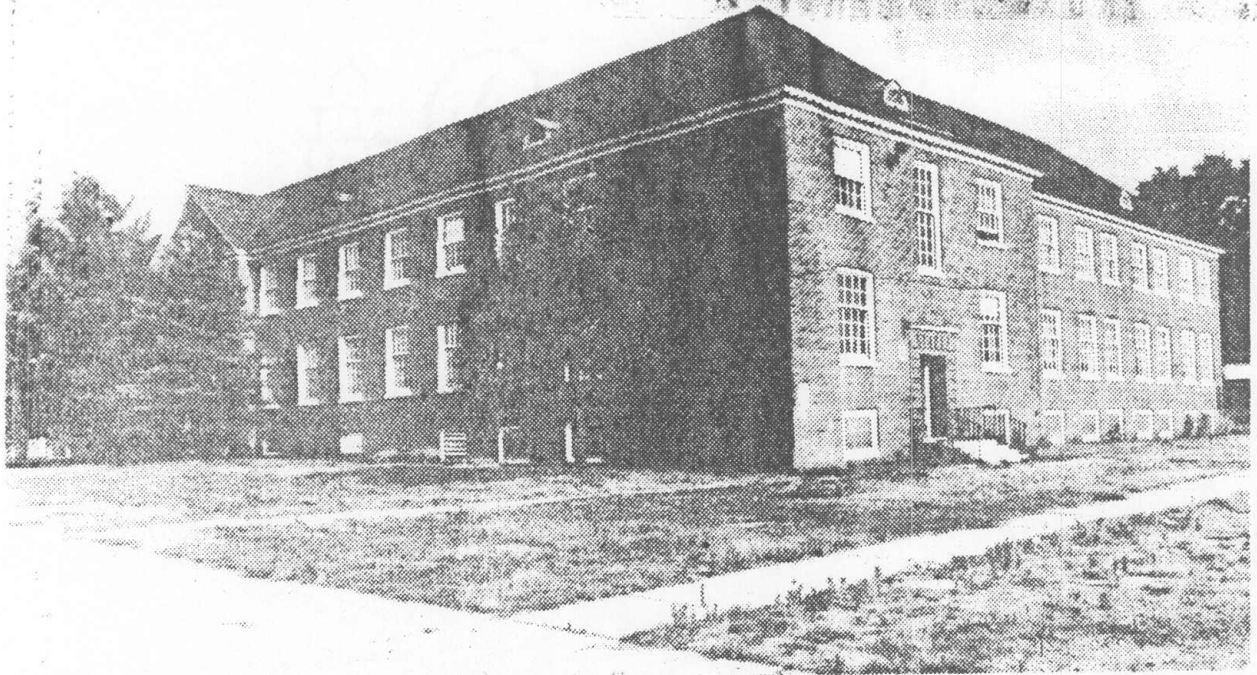
"These are critical years," said Joel Levy, executive director of the Young Adult Institute in Manhattan. "The question, of course, is whether the state will be able to achieve what was planned out. History shows they haven't done that in the past."

"It just depends on your perspective," said Ms. McGraw at OMRDD. "The dreams are being fulfilled, but not as fast as parents would like to see it happen."

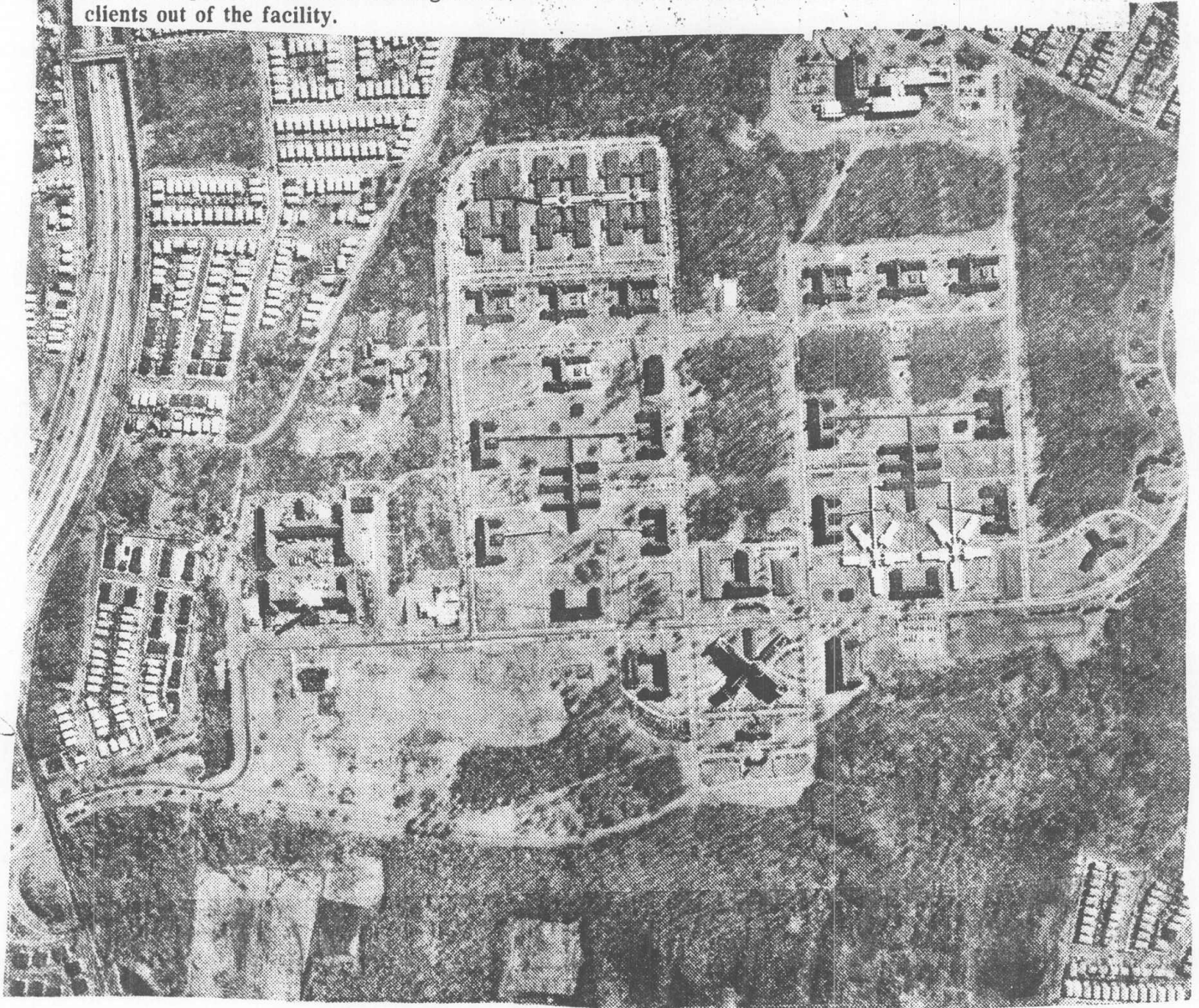
"Are expectations unrealistic? Yes, although it pains me to say that. It's got to be difficult to raise a mentally retarded child, and we certainly have to be sensitive to that. But from the state's perspective, we can't do anything more than what we are doing right now."

This is the first in a series of articles.

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The developmental center's Building No. 21, which has been abandoned in the state's program to move clients out of the facility.



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