

# Willowbrook's Goals Still Unmet 6 Years After Order for Reforms

By DUDLEY CLENDINEN

In 1975 a Federal judge ordered the state to clean up the Willowbrook State School on Staten Island, then the world's largest treatment center for the mentally retarded.

The order, which was to be carried out by March 31, 1981, gave the force of law to a settlement reached between the state and the parents of retarded people; over the next few years, its terms became a model for reform of mental health care elsewhere around the country.

At the time of the lawsuit 5,400 people were housed in what the court found to be appalling conditions at Willowbrook, which was designed to accommodate 1,800. The judge, Orrin G. Judd, set out to change that.

"Within six years from the date of this judgment," he decreed, "Willowbrook shall be reduced to an institution of 250 or fewer beds," to serve the retarded of Staten Island only.

Six years later Willowbrook is in many ways a better place. But with the passing of the court's deadline, the goals have not

been fully met, and the panel established to see that they were has disbanded because the State Legislature failed to provide money for it in the last two budgets.

Last week the New York chapter of the American Civil Liberties Union and the State Department of Mental Retardation and Developmental Disabilities filed cross motions in Federal court concerning the review panel. The Civil Liberties Union, which brought the original suit in

1972, is seeking to force the state to enforce the court order. The state asked the court to end the requirement that mental patients be moved from the institution to smaller residences.

In his 1975 ruling in Federal District Court, Judge Judd, who died in July 1976, set forth not only the rights to which the retarded were entitled and made them official policy, but he also forecast in great detail the changes those policies would implement and the schedule by which those changes should be made.

"The primary goal of Willowbrook," he wrote, "shall be to ready each resident, with due regard for his or her own disabilities and with full appreciation for his or her own capabilities for development, for life in the community at large."

The difficulties of enforcing humane and radical change by Federal decree are plain. By the state's own count, almost 1,400 of those at Willowbrook in 1972, when the suit was filed, are still there. About 940 are under state care in what is now called the Staten Island Developmental Center but is still known as Willowbrook. About 450 others are under the separate care of the United Cerebral Palsy organization in what is called the Karl D. Warner facility.

Roughly 1,000 are still scattered through an array of other state institutions, and about 1,800 have been placed in the community, either in the care of existing families or in group homes bought or leased and staffed by the state or by private agencies. The rest have died or been discharged. As the residential population at Willowbrook has decreased, buildings have been shut, and a study is under way to determine how best to use the 300-acre campus.

The review panel, which for several years after the judgment monitored the state's progress in carrying out the goals has been rendered inert. Its professional staff, which conducted periodic audits, was eliminated when the State Legislature refused to renew its \$340,000 budget last year.

## Review Panel Defended

"We were an arm of the court technically," said Murray Schneps, a lawyer and member of the panel whose daughter was admitted to Willowbrook in 1969 and now lives in a group home outside. "It was fabulous. And it worked, too."

Before the Legislature eliminated the panel's budget, the state was making good progress, according to David J. Rothman, a Columbia University professor of history who has been studying the progress of the work under grants from the Field Foundation and the National Institute of Mental Health.

"Between 1976 and 1979 it was very exciting as a model," he said. "A lot of the ex-Willowbrook residents were moving into the community. It was fascinating, and it was illustrating that you can depopulate an institution without simply creating bag ladies."

"This is a new, different and very important stage in which the question is whether the models established in the 1976 to 1979 period will be maintained. It is very important in terms of whether court-initiated reform can survive in politics."

That question had been in negotiation in Albany, where Governor Carey's office had been attempting to draw a special bill from the Legislature to restore some form of the review panel. The United States Court of Appeals for the Second

Circuit has ruled that the Federal judiciary cannot force the state to spend money that the Legislature has not authorized.

On Friday the State Senate leadership refused again to consider financing the panel. In a letter to Mr. Carey, the majority leader, Senator Warren M. Anderson, Republican of Binghamton, said that the panel was a "needless expense" and that it "perhaps has outlived its usefulness as a monitor of state progress in meeting the terms of the Willowbrook consent order."

In response, the New York chapter of the Civil Liberties Union asked a Federal court in Brooklyn to appoint an overseer to monitor state compliance with the 1975 decree.

The union charged "massive noncompliance with the consent judgment" and asserted that the state could have complied with it, according to Chris Hansen, a lawyer for the organization.

## Negligent Deaths Charged

The group also charged that failure to comply with the decree had resulted in several deaths of residents through neglect and mismanagement, including an incident last July in which a resident fell from a second-story window at the center and later died of his injuries.

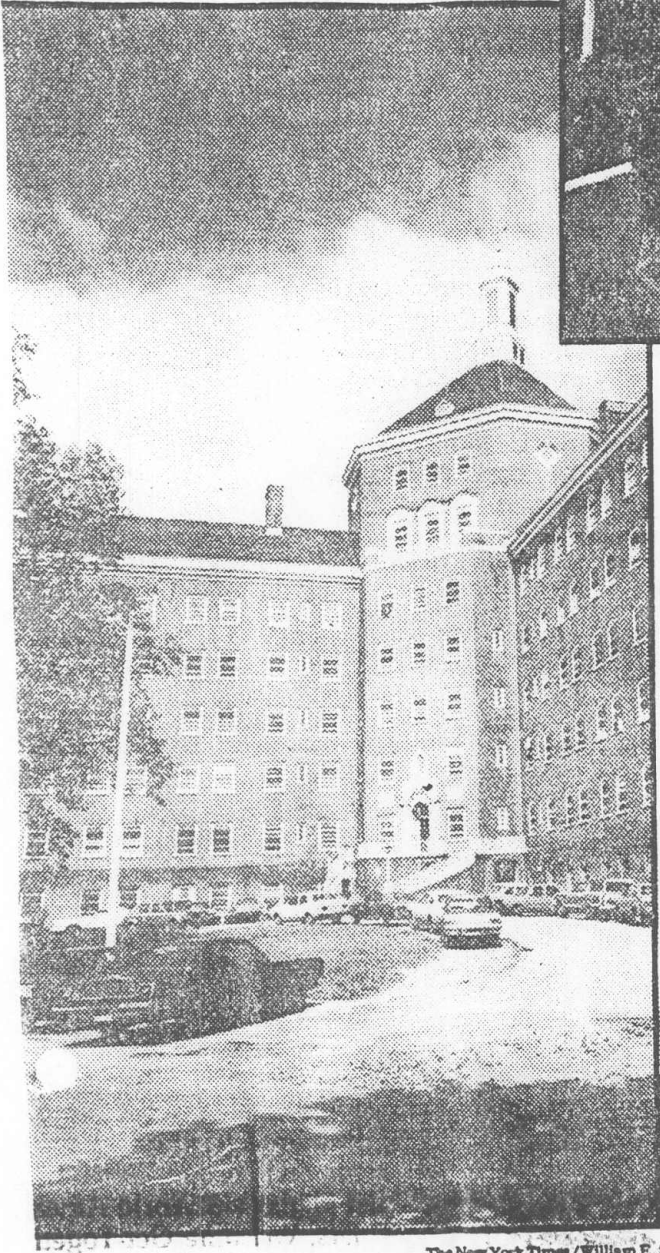
James S. Introne, the State Commissioner of the Office of Mental Retardation and Developmental Disabilities, said Saturday that the state, in its request to the court on Friday, had asked "for an extension of two years on the rundown of Staten Island to 250 beds."

He said the state had also asked the court to allow it to place the remaining severely and profoundly retarded clients in "intermediate care-type facilities of 50 beds — depending on the need of the client."

The 1975 judgment required that they be housed in community group facilities of no more than 10 beds, "and we think it is primarily this limitation that has slowed down the placement of clients," Mr. In-

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At the Staten Island Developmental Center, formerly called the Willowbrook State School, a patient works under supervision in the greenhouse. Hands on the shoulders of those in front, patients walk through a corridor to a class.



The New York Times/William E. Sauro

trone argued. "Now we're in the position of trying to play catch up."

"It is becoming virtually impossible to find appropriate housing stock in New York City to meet institutional code requirements," he said, "and where it is available, it is extraordinarily expensive."

State Senator Frank Padavan, chairman of the Senate's Mental Hygiene Committee, is among those who have questioned the panel's usefulness. He has said repeatedly that the panel engaged in questionable practices, such as placing small groups of "profoundly retarded youngsters" in costly, high-rise apartments that were unsuitable clinically. He and other critics contend that such actions were unrealistic and were taken only to meet the court-imposed deadline.

Meanwhile there is some evidence that in the absence of the panel, the rate of movement of the retarded into the community has slowed. The court, in subsequent orders, set a specific schedule for that exodus — a schedule to which the state agreed, as in a September 1978 order: "All defendants hereby stipulate that absent extraordinary circumstances, unforeseen at present, other than impediments to community placement which have previously been reported to the court, the agreed 50 placements per month are entirely feasible and will be made by defendants."

Rarely has that happened. State records show that in 1978 the state should have found community homes for 666 of its retarded "clients," as they now are called. It actually placed 401, or 60 percent of the goal. In 1979 it achieved 62 percent of the movement ordered by the court. In 1980 the rate dropped to 48 percent. And since April 1980, when the review panel staff stopped functioning, the state has placed only 36 percent of what the court intended at a rate that has varied from 53 down to 11 per month.

"At the present rate of placement, the deinstitutionalization process at Willowbrook will not be completed for at least another eight years," said Mr. Hansen of the Civil Liberties Union.

In the midst of such high aims and mixed difficulties, the story of greatest dedication may be Al Gfadt's, a psychologist at the center. Every working day for the last three years Mr. Gfadt and his staff have been engaged in a necessary but unpleasant task of commitment: toilet training the untutored, the severely and profoundly retarded people who remain here under state care.

At the end of 1977, with almost 2,000 of the brighter members of the old Willowbrook population already transferred elsewhere, Mr. Gfadt designed and began to administer an ambitious program to teach that basic discipline of community life to hundreds of people who are physi-

cally adult but intellectually infantile.

The instruction is based on a reward system for which the main reward is a cookie. The training is endlessly repetitious. It can take as much as a year of 12-hour days to teach a profoundly retarded person the habit of recognizing a basic urge and reacting appropriately.

One recent afternoon, as one of his pupils, a 55-year-old man, shouted nearby, Mr. Gfadt said of the program: "When we began, there was a real sense of urgency. Well, the urgency is certainly gone — and the enthusiasm."

What began as an act of faith in the possible has been frustrated by the implacable. "The placements haven't been opening up in the community with the frequency or scope that was intended," he said. "Of the 67 people we've trained in this program, only two have been placed."

And 53 percent of the rest, he said, have regressed. Sometimes it happens when his pupils complete their training and are sent on to other training programs where the structure is different, he said, "and the bathrooms may be inaccessible."

#### Complex Responsibilities

The responsibilities involved in caring for the retarded and finding homes in neighborhoods for them are bureaucratic and complex. It is not the Staten Island Developmental Center's function, for instance, to find a place in some community home for all the residents still at Willowbrook. "It is the responsibility of the client's borough of origin to develop these sites and to resettle these clients in their own boroughs," said Dr. Ella Curry, the new director of the center.

Invariably some people who live in those neighborhoods fight the move.

"There are hundreds of arguments," said William P. Dwyer, who has worked to locate homes in Westchester County for the Developmental Disabilities Service Office there. "When we looked at a house up in Bedford, we were told that this was

horse country and the retarded people could get stepped on by the horses. They don't want to come out and say, 'We don't want retarded people here.' So they come up with all these smoke screens."

Roy Campanella, the former catcher for the Brooklyn Dodgers, sold his house of 15 rooms in Greenburgh to the state for \$90,000 several years ago. The house is handsome and private, and the grounds are well-kept and splashed with flower beds. But when eight men ranging from moderately to severely retarded were installed inside, the house was picketed by residents of the neighborhood.

#### Spite Reaction in Neighborhood

And when state officials on Staten Island attempted to place three retarded people in a house the state owned in the Emerson Hill section of the island, a group of neighbors filed a civil suit to stop it. They lost, and when the men moved in, one neighbor parked his Cadillac at the bottom of a common driveway to block access for the house staff and the van used to transport the house's residents.

In the massive brick buildings of the sprawling old Willowbrook campus itself, the problems are more grim. Prison-like in architecture, the huge institution stands as an anachronism in mid-transition, a mingling ground of hope, accomplishment, dispiritedness and gloom.

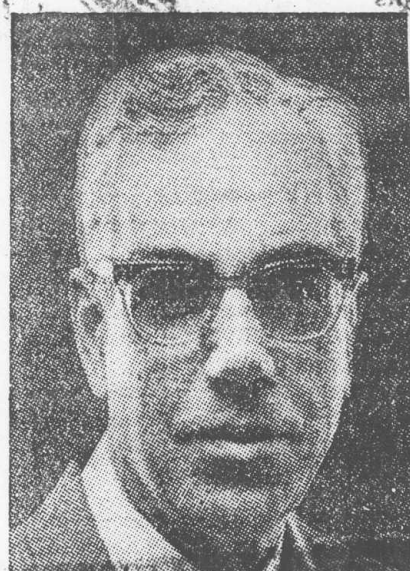
In comparison with the way it used to be — with the chaos, the filth, the overcrowding and the neglect that were so common a decade ago when it held 5,000 to 6,000 patients, as they were then called — the improvements are stunning. The institution is a sparser, cleaner, better-tended version of its former teeming self. Medical care is vastly improved, and every resident is required by the court to be given six hours of useful instruction every day.

#### Severe Cases Remain

"Everyone has a potential," said Dr. Curry, who took the director's post last November, "and we have a duty to help them reach that potential and to keep it." But the transfer out of thousands of the brighter clients — many of whom, by general agreement now, never needed to be committed in the first place — has left the most severely and profoundly retarded people behind. More than 300 of the 940 remaining are also multiple handicapped, their muscles atrophied and their bodies contorted by birth defects and years of previous neglect.

The large wood-working shop in the school building is closed and locked. Inside, its drills and saws and cutting tools gather dust. The classes in reading, writing, arithmetic and social studies that were taught when there were better-functioning residents at the facility no longer exist. The garden they used to tend has gone to weed. And staff morale, for those reasons and the fear of job loss as the phase-out continues, is critically low.

"The message is, here is a place that's dying," Dr. Curry said. "You look around, and it looks like it's dying."



The New York Times  
Judge Orrin G. Judd in 1973

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