

A look back

Carey made Willowbrook a priority

By JULIE MACK
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Peter Goldmark had been state budget director for only three days when the Willowbrook lawsuit was tossed onto his desk.

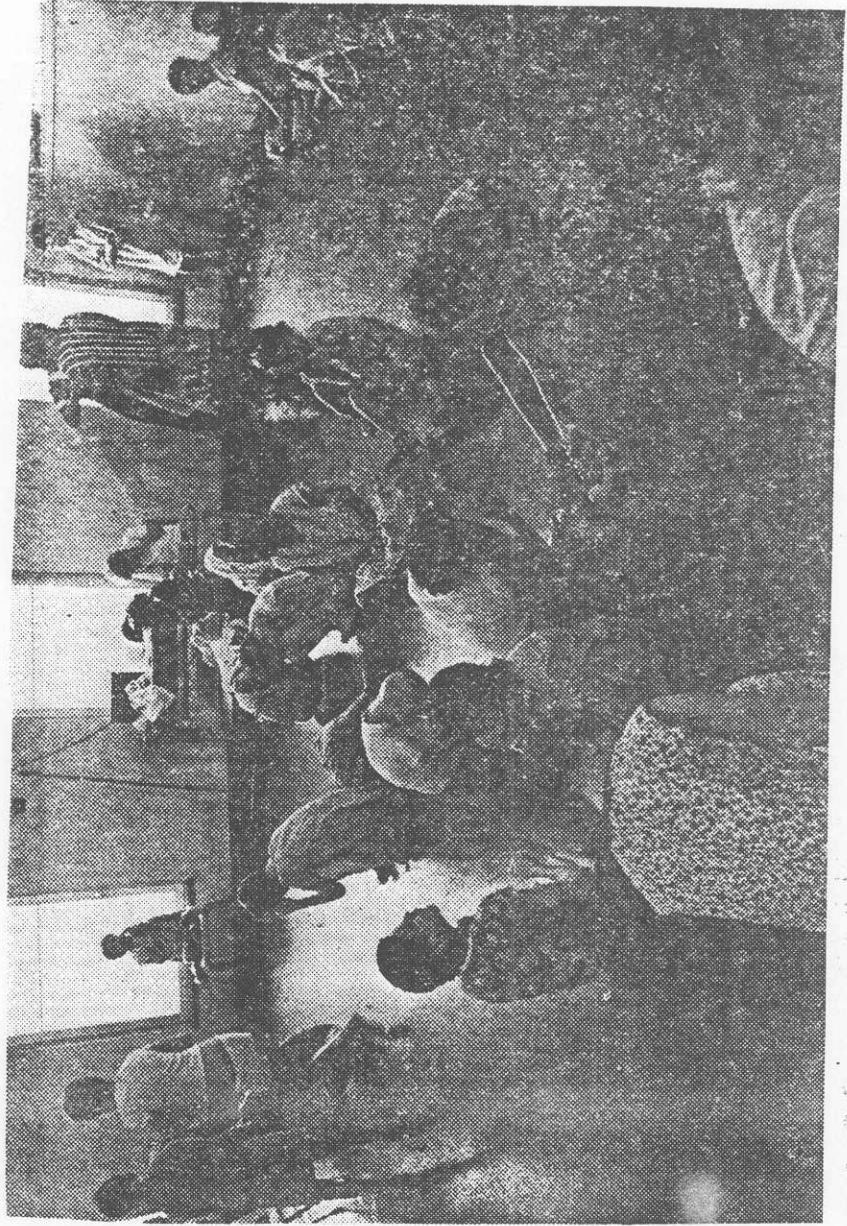
This was 1975, and Goldmark was part of the new administration brought in by Hugh Carey,

who had just won the governor's seat. Carey had made a campaign pledge to upgrade conditions at Willowbrook State School (now called the Staten Island Developmental Center) and he was ready to use his office to improve life for the mentally retarded.

"It was a matter of philoso-

phy," said Arthur Webb, the current commissioner of the state Office of Mental Retardation and Developmental Disabilities. "Carey thought the Rockefeller administration had two black marks against it — the uprising at Attica (state prison) and the policy on mental retardation, which was a disaster."

Before taking the job as Carey's budget director, Goldmark served as head of human services in Massachusetts. In that capacity, he negotiated a consent decree to settle a lawsuit involving a Massachusetts institution for the mentally retarded. Now he was asked to do



Girls in Willowbrook sit in a large bare, room and wait for their next meal in this 1971 photo. S. I. Advance Photo

the same for New York.

The Willowbrook lawsuit was filed in March 1972 by the New York Civil Liberties Union (NYCLU) and the Legal Aid Society at a time when the institution's deplorable conditions were making headlines across the state and parents of patients were demanding action.

The formal complaint put before Judge Orrin Judd in U.S. District Court in Brooklyn, which was filed on behalf of the 5,343 residents at Willowbrook, challenged "the adequacy and constitutionality of conditions" at the institution.

Bruce Ennis, who headed the legal team for the plaintiffs, hoped the suit would upgrade client care at Willowbrook; the ultimate goal was to force the state to close Willowbrook and its other institutions and resettle the mentally retarded into the community.

By the time Goldmark became involved, the lawsuit had bounced around in the federal court for three years without a satisfactory resolution. While the NYCLU obtained timetables on such items as increasing the Willowbrook staff and putting a freeze on admissions, the lawyers doubted conditions at Willowbrook had actually improved.

In addition, the NYCLU was alarmed by the way the state was relieving the overcrowding at Willowbrook. Between 1972 and 1975, the institution's population had dropped from 5,300 to 2,900. But only eight residents were placed in group homes; most were transferred to other institutional settings. Some were placed in vacant wards at state mental hospitals, and others went to boarding or nursing homes. More than half were simply transferred to other state institutions for the retarded. It wasn't what the NYCLU had in mind at all.

Moreover, the very manner in which residents left the institution was disturbing — even to the Willowbrook staff. Genevieve Benoit, a supervisor at the center during the 1970s, remembers people walking into a ward and arbitrarily pointing out residents, "I'll take you and you and you." People were taken away in such haphazard fashion that staff were sometimes unsure of who had left or where they had gone.

"You would go into a ward and say, 'Where's Jane? She was here yesterday.' And people would sort of shrug their shoulders and say, 'I don't know. Where *did* Jane go?'" Ms. Benoit recalled.

(The patient exodus later provided Ms. Benoit with the name of the non-profit agency she formed with colleague Diane Buglioli after they left Willow-

brook.

(As Ms. Buglioli explains it: "We were working in a ward with kids, and when everything started happening, we decided that we had to prepare these kids for leaving Willowbrook. So we told the kids how wonderful their new home was going to be. I would tell them that they were going to a very special place. And when we formed the agency, that's what we called — A Very Special Place." The agency, headquartered in Dongan Hills, provides training and recreational programs for the mentally retarded.)

The NYCLU lawsuit went to trial in the fall of 1974. While the state argued that the squalor had been eliminated, their arguments were undermined by a host of witnesses for the plaintiffs who told horror story after horror story.

One particularly gruesome piece of testimony came from a nurse who helped remove the cast from the leg of a Willowbrook resident; when the cast was removed, maggots were found festering underneath.

As the trial began, the state and the NYCLU were attempting to negotiate a settlement, but that was complicated by the 1974 elections and resulting change in governor.

Actually, the change seemed to benefit the plaintiffs, according to Chris Hansen of the NYCLU. Carey was more willing than his predecessors to resolve Willowbrook's problems, Hansen said.

Carey called in Goldmark, and in 1975 the negotiations began in earnest. Goldmark says that from the start his goals matched those of Ennis, who led the NYCLU team — both wanted the consent judgment to ultimately empty Willowbrook and build a new system of community residences.

"I thought that was the only way to care for the mentally retarded," Goldmark said. But there were details to hammer out and Goldmark's time and energy were sapped by the budget crisis unfolding in New York City.

"Goldmark was in the midst of the fiscal crisis and we weren't," Hansen recalled. "We were holding meetings with him at 8 o'clock at night. It wasn't so bad for us — we would go home and rest and be fresh for the negotiations, but he wasn't."

As a result, Hansen said, Goldmark was "extremely willing to listen" to the NYCLU's suggestions for the consent decree, and the NYCLU was able to achieve many of its objectives in the final document.

"If Rockefeller had stayed in office, I don't think we would have had a settlement," Hansen said.

The final document was 29

pages and very specific in terms of improvements to be implemented at Willowbrook. Training and recreational programs, medical care, client-staff ratios, the amount of clothing, the length of meal times were all spelled out in minute detail.

The document noted that the state would continue to move residents out of Willowbrook, and that the institution's population would drop to 250 residents, all native Staten Islanders, by 1981. The others would move into community residences of 15 beds or less.

The document was approved

by the NYCLU and the state in the spring of 1975, and put before Judd, who signed his name on April 30, putting the consent judgment into effect.

"I was basically satisfied," Goldmark said. "The consent judgment was a good compromise. It was worth all the grief, all the friction."

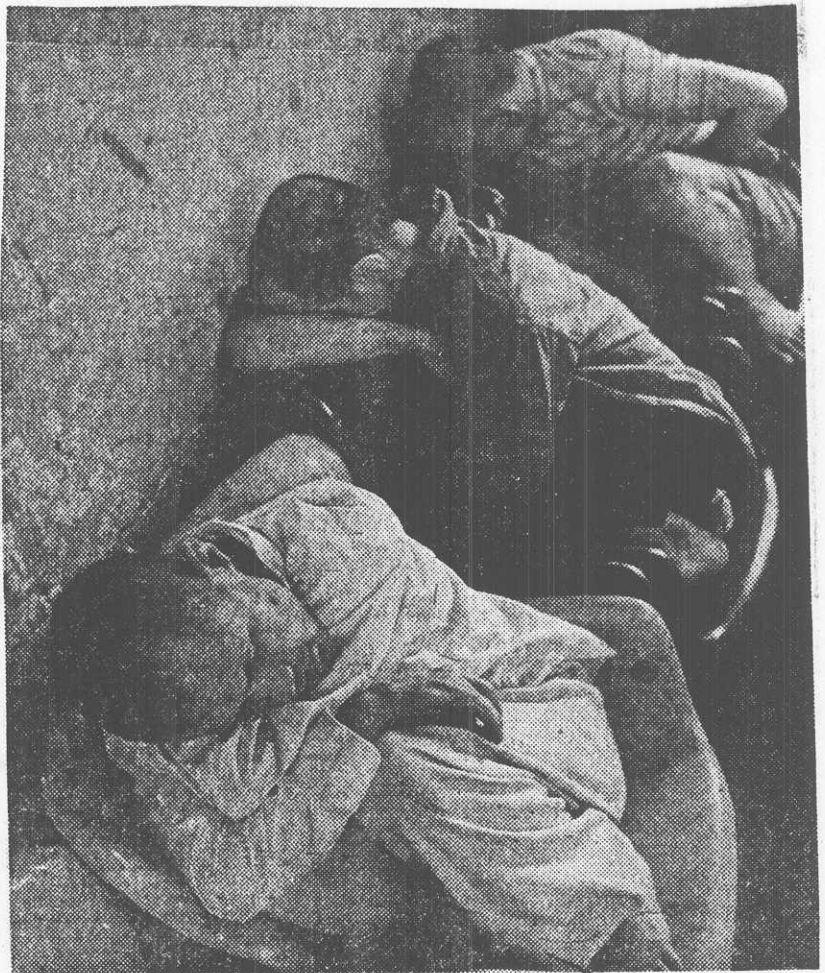
The NYCLU was also pleased with the consent judgment, Hansen said, although in retrospect its enthusiasm proved to overly optimistic.

"We really thought all the improvements could be implemented within 13 months, as the

state promised. We really thought that the institution's population could drop to 250 by 1981," Hansen said. "We anticipated difficulties, but didn't come close to anticipating how serious those difficulties would be."

As Hansen would find out, the consent decree did not settle the Willowbrook case. It merely started a new chapter.

(This is the third in a six-part series on the Staten Island Development Center and what has happened to it since the consent decree was issued 10 years ago.)



Men with shaved heads curl up in chairs and hide their faces in this ward in Willowbrook in 1972.