

## A look back

# Willowbrook caught in national spotlight

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When Michael Wilkens joined the medical staff at Willowbrook State School, he had no idea he would help father a revolution.

It was the summer of 1970, and the 28-year-old Kansas City native was finishing his third year in a residency program at the U.S. Public Health Service Hospital in Clifton. Dr. Wilkens was looking for a change and he was looking to stay on Staten Island; the Willowbrook job fit the criteria.

Moreover, working with Willowbrook's mentally retarded residents appealed to Dr. Wilkens' youthful idealism. He wanted more than to just practice medicine; like many of his generation, he wanted to participate in social reform.

But despite his vague notions of activism, Dr. Wilkens really had no concept of what Willowbrook was like. His first day at work — he was assigned to Building 6, considered one of the worst wards — he was jolted by the overcrowding, the utter lack of available resources, the wail of patients and the terrible stench.

"I was really taken aback that it was so wild," he recalled. "The worst part of it for me was the confinement. It was a jail for those patients, a lifelong jail."

Most new employees at Willowbrook had the same reaction, Dr. Wilkens said. But after the initial shock, others grew to accept the situation. By contrast, Dr. Wilkens decided that something had to be done, and he was ready to lead the charge.

Among those in the field, it was no secret that Willowbrook was little more than a human warehouse. The problems were well-documented: The horrible overcrowding and the frightful understaffing; the poor hygiene

which resulted in continual epidemics of hepatitis; the inadequate training and recreational programs; the mysterious injuries suffered by residents; the everyday abuse and neglect.

Willowbrook was swathed in controversy from the day it opened. Construction on the facility began in the late 1930s, but by the time it was completed, the country was at war and the federal government took over the institution to create Halloran General Hospital. After the war, the campus was used by the Veterans Administration and it wasn't until 1951 that the state wrested back control of the facility and opened Willowbrook State School.

The problems began immediately. Because Willowbrook was built to relieve overcrowding, other state institutions were invited to transfer patients to the new institution; it is not surprising that many sent their most difficult and most severely handicapped patients. From the start, Willowbrook held a greater percentage of the profoundly retarded than any other state facility; by 1969, three-fourths of Willowbrook patients were profoundly or severely retarded.

Some said Willowbrook received less resources because its patients were considered hopeless. Yet in the early days, the facility did not have a bad reputation — occasionally, parents from outside New York would abandon a handicapped child at Grand Central Station so the child could be placed at the "renowned" Staten Island institution.

But by the 1960s, it became apparent that Willowbrook was troubled. In 1964, a state legislative committee toured Willowbrook, witnessed the conditions first-hand and wrote a critical

report. The following year, a series of violent deaths inspired media coverage and a grand jury investigation. That was the same year Sen. Robert Kennedy made a surprise visit to Willowbrook and scathingly compared the facility to a zoo.

When Dr. Wilkens arrived on the scene, the conditions were no worse than in the 1960s — in fact, the numbers were beginning to look a little better. In 1971 Willowbrook had about 5,300 patients in a facility meant for 4,500; in 1964 the institution had had 6,400 patients — and a thousand fewer employees.

But Dr. Wilkens was not persuaded by the philosophy of the Willowbrook administration that the state had neither the money nor the desire for further improvements, and he found an ally in another young doctor, William Bronston, who was already earning a reputation as a rabble-rouser. Like Dr. Wilkens, Dr. Bronston was outraged by the conditions at Willowbrook and made no bones about the changes he thought necessary.

The key, Dr. Wilkens and Dr. Bronston figured, was the establishment of community services. Although the theories were relatively new at the time, Dr. Bronston in particular was familiar with studies showing that the mentally retarded could achieve remarkable progress in community programs which emphasized "normalization."

Dr. Wilkens and Dr. Bronston thought the best way to pressure the state to start such programs was by organizing a reformist movement among the Willowbrook employees. They talked with colleagues; called meetings, even sponsored seminars with guest speakers who were familiar with community programs for the retarded.

"We tried — we really tried," Dr. Wilkens said, "but the response was zip. They probably didn't like newcomers coming in with what they regarded as covert hints that things hadn't been done right in the past."

The other doctors were the most hostile, perhaps because they felt most threatened by any sort of reform which would close the institution. Dr. Wilkens said, "They didn't want to make waves and they just didn't agree with us."

Most of the staff felt the patients weren't capable of doing anything. We would tell them about the benefits of special training and special types of positive environment and they wouldn't believe it."

Dr. Wilkens and Dr. Bronston did get some positive feedback from the professional staff at Willowbrook — the teachers, therapists and the social workers who knew from their own experiences about the potential of the retarded — but the handful of supporters was not enough, and Dr. Wilkens and Dr. Bronston were forced to change strategy.

They decided to make contact with the parents of Willowbrook patients — a risky proposition, considering that the parents' reputation for passivity at that time matched that of the Willowbrook staff.

The parents considered themselves "hostages to the state." Anthony Pinto, leader of the Willowbrook Benevolent Society, said.

"Parents accepted the philosophy that a retarded child was something to be ashamed of, that isolation was the best thing," Pinto said. "And there was such competition for beds at the few available facilities. There were long waiting lists to place your child at Willowbrook. Parents thought that if they complained, there was the threat their child would be sent home," Pinto said, adding, "they were more interested in currying favors for their child."

Dr. Wilkens and Dr. Bronston tried to crack the inertia among the parents by holding outdoor cookouts on Sundays, the day parents would visit. The first cookout was held in the spring of 1971; one parent came. The same parent was the only guest on the second Sunday.

"The parents weren't interested," Dr. Wilkens said. "They had seen gestures made that fizzled out and they were tired. They doubted we were their friends.

"But we kept holding the wienie roasts every Sunday. Soon we had a core of four families who would come. We started to have speakers come to talk about what the retarded needed.

We also let the parents talk about their experiences. The attendance (at the Sunday meetings) grew because parents were hungry for support and they needed a vehicle to express their pain."

By fall of 1971, the meetings were growing by word of mouth, Dr. Wilkens said. About the same time, the budget cuts by the Rockefeller administration were beginning to have a painful effect on resident care at Willowbrook.

What happened next surprised even Dr. Wilkens and Dr. Bronston. "It was one of those situations where there is a group dynamic and parents began to feed off the changes in each other. They went from being very passive and feeling hopeless to being very militant," Dr. Wilkens said.

November was a turning point. The parents, encouraged by Dr. Wilkens and Dr. Bronston, picketed Willowbrook. Now only did that make the Willowbrook administration take notice, but it got the attention of the media.

Advance reporter Jane Kurtin covered the march, and "she was the first person from outside Willowbrook who really seemed to care," Dr. Wilkens said.

Dr. Wilkens and Dr. Bronston took the reporter on a tour of the institution; Miss Kurtin was properly horrified and fired off a series of expose-type articles about the conditions. "We were running over with information for her; we were just so eager," Dr. Wilkens said. "We were beginning to feel like we were crazy, then she came and wrote these stories. It sort of validated our internal feelings that we were on the right track."

In December, there were more meetings, more parent protests, more stories in the Advance about Willowbrook; the Willowbrook administration began to get twitchy. Then the parents had a meeting in which they invited the director, Jack Hammond, to get "his side of the story."

"His side of the story was that he had been in the field for many years, he had seen a lot of efforts for reform come and go, then he had seen Kennedy come — he had seen a lot. And it was his impression that no good ever came of that type of thing; that it was always just a flash in the pan," Dr. Wilkens said.

It was not what the Willowbrook parents wanted to hear; they told Hammond to go on record as saying that conditions at the institution were unacceptable, and to demand more funding. "Hammond said no; he was really put off by the 'unacceptable' clause and he said it wasn't the way to make change," Dr. Wilkens said. "When he said that, the parents expelled him from the meeting."

Furious, Hammond told Dr. Wilkens and his cohorts on the staff to quit meeting with the parents. The employees ignored the ultimatum. On Jan. 5, Dr. Wilkens and social worker Elizabeth Lee were fired; because they were provisional employees and lacked union protection, Hammond did not have to justify their dismissal.

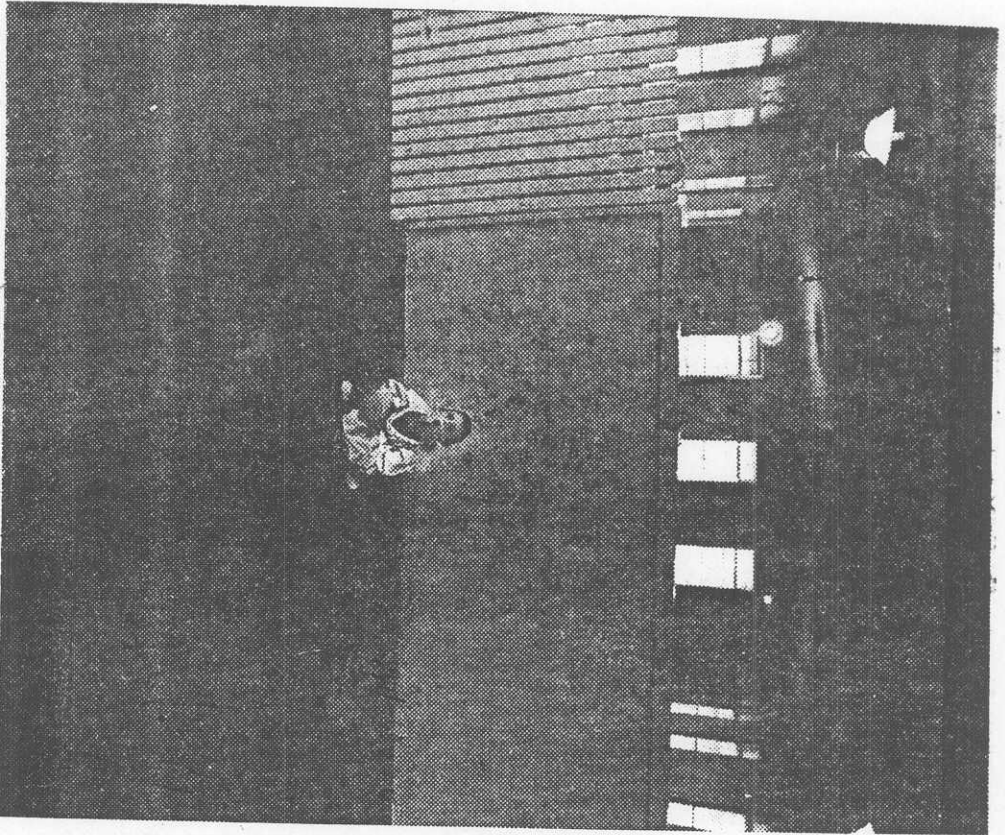
The next day, Dr. Wilkens called a friend who was a new reporter for ABC television. The reporter, Geraldo Rivera, made his first trip to Willowbrook on Jan. 6; the institution made the 6 p.m. news that night.

Although the Advance was writing about Willowbrook for almost two months before Rivera's report (48 articles, editorials and letters to the editor concerning the institution were published in that seven-week period), the television coverage had a new impact.

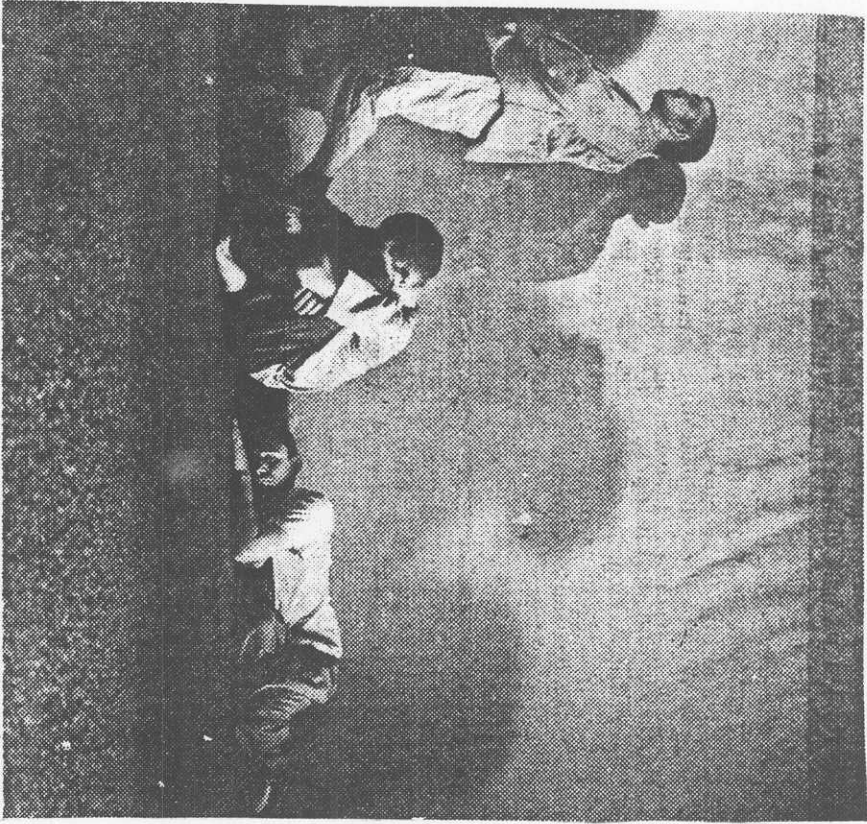
Those first frantic months of 1972 were exhilarating to those leading the call for reform. The media coverage and parent protests escalated — a rally on Jan. 11 ended with parents storming the Willowbrook administrative offices — and it became apparent that unlike 1965, the attention on Willowbrook was not going to dissipate until something was done.

But there was also a backlash aimed at the Benevolent Society. Many Willowbrook employees, resentful of the media coverage, muttered that the parents didn't understand. The head of the New York State Association for Retarded Children charged that the Benevolent Society had become infiltrated by the SDS, a radical student group.





A lone child sits and cries on the floor of the Willowbrook State School in the days before the consent decree. S. I. Advance Photo



Adult Willowbrook patients, wandering or lying on the floor, are left to themselves with nothing to do in this 1972 photo. S. I. Advance Photo

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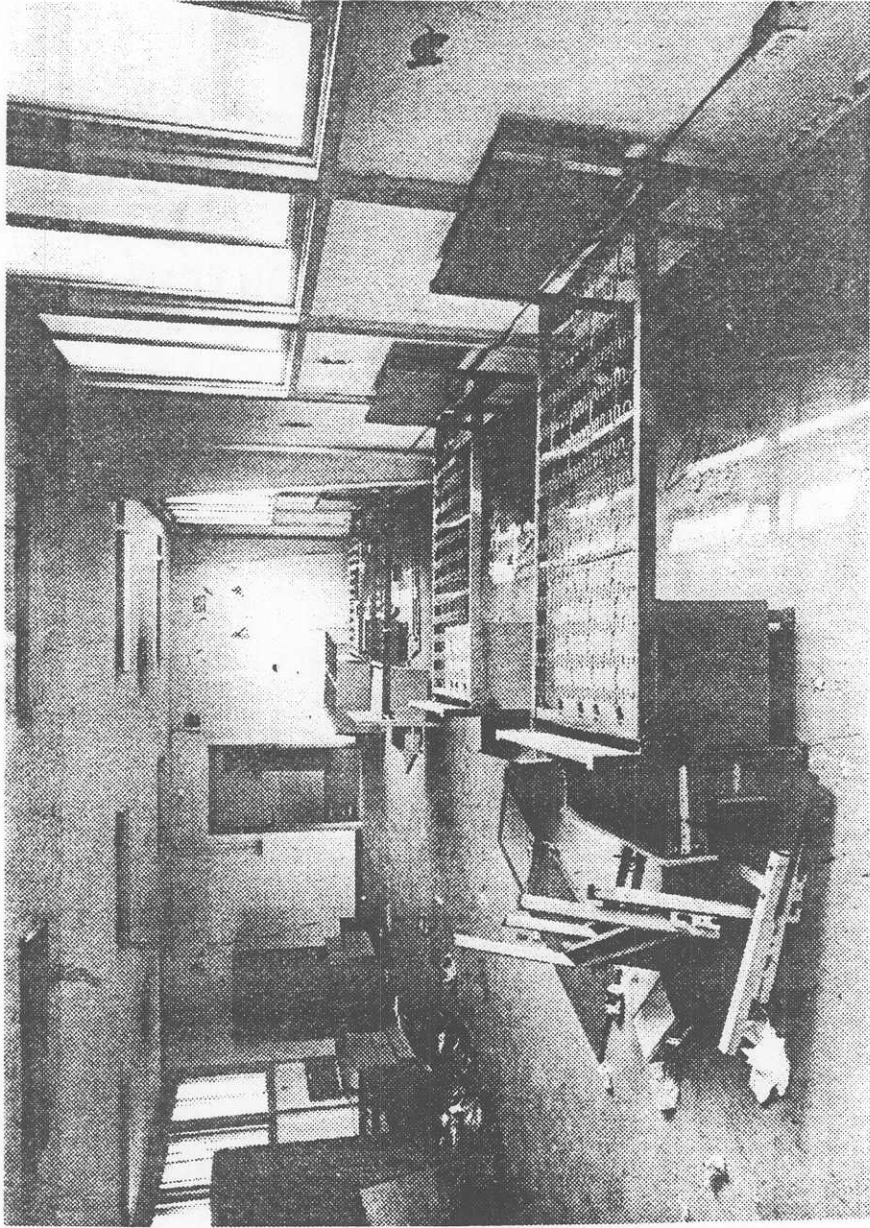
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**Beds cramed together with no more than three inches between them show the crowding that existed in Willowbrook as late as 1975.**

S. I. Advance Photo

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**Bedframes and a few old personal items are strewn about Building 76, a "pre-fab" structure at the Staten Island Developmental Center that has been abandoned for several years.**

**S.I. Advance Photo by Tony Dugal**

Besides, some parents of Willowbrook patients simply questioned the wisdom of pushing for change. Willowbrook had problems, no question about it, but it was the only resource available to parents and some were frightened about jeopardizing its future.

But the Benevolent Society leadership stuck to its guns and continued its battle cry. Meanwhile, politicians began promising investigations of the institution. Even more significantly, Robert Feldt of the Staten Island office of the Legal Aid Society and Bruce Ennis of the New York Civil Liberties Union began meeting with parents to discuss possible court action.

In March, a class action lawsuit was filed on behalf of Willowbrook patients in U.S. District Court in Brooklyn. It was the first step of history in the making.

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