

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.