

Thursday, February 10, 1972

Willowbrook: Keepers and Kept, a Single Cage

By Stan Pinkwas
City News Staff Writer

These fought, in any case,
and some believing. . .
. . . then unbelieving
came home, home to a lie,
home to many deceits,
home to old lies and new infamy;
usury age-old and age-thick
and liars in public places.

--Ezra Pound

There are university campuses that are physically uglier than the Willowbrook State School for the Retarded. Kent State is one. Its grim, pollution eaten buildings and blasted greenery make Willowbrook seem almost pleasant. But the killings at Kent State lasted only a few seconds. At Willowbrook, it goes on all the time. The weapons are budget cuts and lies, slower than bullets but just as effective.

A *New York Times* reporter asked Dr. Jack Hammond, Willowbrook's director, if it was true that patients were dying because there weren't enough nurses or ward attendants to care for them. Dr. Hammond said, "We do have a rare death because of a patient having a convulsion and then aspirating his own vomit."

How rare? asked the reporter. "Three of four times a month," said Hammond.

Willowbrook is everybody's problem, including Co-op City's. There are at least 15 families in the community with children at Willowbrook and others with children at Letchworth and other state euphemisms for the retarded.

Three months ago, Willowbrook was the skeleton in New York's budgetary closet. But now that the bones are rattling in the fresh air, it's a different story. The politicians who approved the 1972-73 state budget, like relatives at the reading of a will, have suddenly found in Willowbrook a shortchanged second cousin and a new subject for press releases.

Last Saturday there was a rally at Willowbrook. It was a bitter cold Alpine bright day. The rally was supposed to be indoors. The State Department of Mental Hygiene said it would be outdoors and about

200 people and several speakers fought a Co-op City style wind beside a placid iced over lake.

"Congressman Murphy would like to say a few words. I hope he doesn't have anything good to say about the institution."

He didn't and neither did anyone else. If rhetoric could warm bodies, it would have been a beach day. Congresswoman Bella Abzug was the loudest speaker.

"We all know that Willowbrook is an obscenity. Rockefeller simply restored a cut he had made in an already reduced budget. It's an old political game. You let conditions deteriorate from the unbearable to the unspeakable and then bring it back up to the merely miserable.

"We must insist that our money be spent on human needs. A society is judged on how well it cares for those who are the least able. We must guarantee that those who can learn are taught. We must begin to phase out huge impersonal institutions like Willowbrook and replace them with small home

facilities... NO WORK
Congressman Edward Koch stood up and demanded that a supreme court judge go through Willowbrook's wards and remove the children who are clearly not retarded. "We have to get a law passed that says people will not be treated like animals."

A representative from Mayor Lindsay's office read a one sentence expression of sympathy. He was lucky to escape alive.

Congressman Mario Biaggi who had said he would be there was on a plane going to Ireland.

Harriet Winter, who has one child at Willowbrook and another at her home in Co-op City, thought the rally was a waste. Belle Lazare, who also has a daughter there, said she wouldn't have come if she'd known it was going to be outside.

And so it goes. Willowbrook has always been a house of pain but the worst began in December 1970 when the state's Division of the Budget dropped a job freeze on the institution. At that point, Willowbrook was already short 279 employees. Within a year, it lost 633 more employees, making it nearly 1000 short and making adequate care, even custodial care, physically impossible.

Conditions all go from the unbearable to the unspeakable. Diseases, such as tapeworm, dysentery, hepatitis and ringworm, which were always prevalent became more prevalent. Staff/morale dropped along with their numbers.

A report in December 1971 by Program Analyst William Jennings for Frederic Grunberg, deputy commissioner for Mental Retardation, called the situation potentially explosive.

Back further, in March, Alan Miller, Mental Hygiene commissioner, sent out a letter to state assemblymen describing what would happen if the freeze continued:

"Many of our state hospitals and schools would be forced back into intolerable conditions from which we have been slowly lifting ourselves over the past decade. Many patients could not receive needed treatment, many would be poorly cared for, some would die. Thousands of retarded children who cannot feed themselves would be poorly fed; thousands more would be denied the personal care they need to live under even marginally decent conditions."

No one listened and the same true.

Irwin Bier, vice president of the Willowbrook Benevolent Society, Co-op City resident and father of a child at Willowbrook, said, "I've been up in Albany several times and the legislators said we were not strong enough, that we didn't have enough pressure behind us."

When I spoke with him, he showed me a letter he received from State Assembly Speaker Perry Duryea in response to a plea for more aid. It was a form letter addressed "Dear Constituent" and sent out in bulk.

It began: "The reductions in the Mental Health budget voted by the Legislature were aimed at administrative and collateral services, not at direct patient care."

"The reductions involved a large public relations staff, consultant services, educational assistance and high level personnel who receive full salaries while on educational leave."

This is a lie. The reductions involved mostly nurses and ward attendants.

"Patient population has decreased 25 per cent over the last five years, while staff has increased as much as 45 per cent."

The state has increased staff without adversely affecting patient care.

Patient population has not decreased. Willowbrook is so crowded now that it will not even admit emergencies. The patient staff ratio could not safely be enlarged.

"The Department (of Mental Hygiene) was granted a 10.7 per cent increase, or \$16 million over the \$150.2 million which they stated to be necessary to maintain their current level of service. In addition, we have approved \$4.6 million for expanded family care, replacement of equipment and other important services."

In actuality, the state lopped \$30 million off the Department's request for \$630 million and froze everything above \$580 million, making for a budget cut of \$50 million.

As for equipment, Willowbrook cannot even afford clothing for its patients. The Benevolent Society, a parents group, donated the money to buy modern hearing therapy equipment the institution would have had to pass up otherwise, plus another \$9,200 for 21 specially equipped wheelchairs.

Duryea ended by saying, "The legislature is sympathetic to the child, but it does not feel the need to spend money."

benefit the public. They merely waste money which could be put to better use.

There have been other lies. The Department of Mental Hygiene tried to deny it knew the severity of the conditions at Willowbrook up until the Jennings report was leaked. Jennings described the Willowbrook horror in vivid detail and said that the Department of Mental Hygiene had been carefully briefed with weekly reports.

There is also Governor Rockefeller's charade of concern. After a tremendous public outcry, he restored \$5 million of the cut \$50 million to the Department's budget. He found the money by borrowing it from next year's budget for the Department.

What will happen next year? No one knows, and when the current wave of publicity dies out, no one may care any more just as legislators stopped caring in the past after similar waves of publicity died out.

Irwin Bier joined the Benevolent Society nine years ago, the first week his child entered Willowbrook. He has been caring ever since to the point where his work in the Benevolent Society has become a second, almost full time job.

"We've been trying for years to educate the public and the parents. There was a time when parents wanted to put their children in places like Willowbrook and forget about them."

"We're past that now but parents are still their own and worst enemies. They leave it to a handful of people to work and work and work."

"The parents understand what the employees and ward personnel are going through and that they are fighting against truly impossible odds and conditions. It is the State Department of Mental Hygiene that is our mortal enemy."

"In April 1971, they decided, without consulting parents or the Benevolent Society, to close down Gouverneur Hospital which has 194 severely and profoundly retarded children and to discharge the staff and return the children to Willowbrook where they originally came from."

"We went down and legally prevented them from removing the children. In the end, the commissioner relented and kept Gouverneur open."

Gouverneur Hospital is one of the State's better institutions and State Supreme Court Justice Samuel

Spiegel decided that closing it down and sending the children to Willowbrook and other overcrowded, understaffed state "schools" would be a crime to both the children and the parents.

"We saved 200 jobs then," said Bier, "and we've got 300 more jobs now that the freeze is over. Because of this, people think the worst is over but it's not. First of all, it's going to take months to absorb this many people back into the system."

"A big institution like Willowbrook is not the answer. It's our contention that mental hygiene has been shortchanged and it has. We're at the bottom of the barrel."

"All I can tell you is ten years of my life is here and it's been the roughest ten years of my life."

At the rally, the loudest roar of approval went to Assemblyman Frank Stella when he shouted, "We're gonna tell Nixon that for every child that dies here, there's gonna be a cross on the front lawn of the White House."

The crowd roared. In the rear, a woman turned to her neighbor. "I'll believe it when I see it" was all she said.