

# The New York Times

SATURDAY, FEBRUARY 26, 1977



Blind residents of Willowbrook walking through the center's grounds. Only weak efforts have been made to develop programs for the blind there.

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# Court-Ordered Winds of Change

## Sweep Willowbrook



A young resident hugs a physical therapist after a session in one of Willowbrook's 27 residence buildings.

By PETER KIHSS

Arlene looked half asleep. But when summoned, she sat down at a miniature xylophone. First she was asked to clap the two rhythm sticks—"One and two and three"—and she did that in time. Then, "Play red." She struck the red musical key, and on following commands played the black and green keys.

Arlene is a retarded child who exemplifies the increased new efforts being made at the controversial Willowbrook Developmental Center on Staten Island to develop each resident to his full potential.

Since 1972, the state facility for the mentally retarded has been the target of a Federal Court suit by parents and civil liberties lawyers, who termed it at the time a place of horror, where people "deteriorated both mentally and physically."

Nowadays, residents and staff members seem to be trying harder. There were 2,600 staff members two or three years ago; now there are 4,350. Dr. Levester Cannon, Willowbrook's director, estimates that, given retirements and departures, perhaps 3,000 are new.

Many of the staff members are young, with more of the hope and idealism of youth. There's more working "one on one" with the 2,500 residents—down from 5,341 when the court case began in 1972. There were still 2,900 residents there when a con-

sent agreement in April 1975 stipulated a reduction to 250, serving only Staten Islanders, in 1981.

Buildings are brighter with fresh paint, curtains on windows, rugs, sofas, new chairs. Wardrobes for each resident divide the former 50-bed wards into groups of sometimes as small as eight. Regular beds have replaced many old hospital cots.

There is new clothing, and just about everybody wears it instead of the hospital gowns of a couple of years ago—when clothes could not even be kept on some. New equipment includes 300 wheelchairs, many individually adapted.

There is still discontent over the rate of progress. One parent, James C. Camen, called the changes mostly "cosmetic." He said the placement of the wardrobes prevented attendants from seeing some residents harass others.

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The New York Times/Neal Boenzi

## A therapist assists a youngster in use of a motor development device

His wife, Genevieve, the current militant president of the Parents Benevolent Association of Willowbrook, said there was up to \$400,000 a year in food and clothing thievery. "There aren't programs as they claim there are," she charged.

There's other discontent. Willowbrook has 30 full-time and 25 part-time physicians. About 30 of the group staged a half-hour protest Wednesday, and then 10 met for two hours with Dr. Cannon over grievances.

They complained of interference by nonphysicians in medical matters, which Dr. Cannon, whose doctorate is in education, disputed. The post of medical director, vacant since August, is being discussed with a voluntary hospital physician.

Jerome W. Isaacs, one of the original plaintiff parents, contended "until there is a separate [New York State] Department of Mental Retardation, with employees taught from the start that these kids can be helped, improvement in the various institutions will not occur."

Jesus Rios, another plaintiff parent, said that "they have tried to improve," but that his son was learning to manage better since his transfer to a group home last November. Rose Regent said her sister, moved to a foster home last October, "is now living like a human being with a wonderful person."

### Decentralization Praised

The court-required concept of decentralizing from the vast 350-acre complex with 27 residence buildings draws praise—for instance, from Sam Babich.

Mr. Babich was exceptional in keeping up with his son at Willowbrook, and since June the son has been living at home in programs that the father said were closely supervised by the State Mental Hygiene Department's metropolitan placement unit.

The Babich family is one of about 100 that is paid \$291 a month for taking relatives back home from Willowbrook. The former residents must attend schools or workshops in a required six-hour daily program.

Mr. Babich's son, who is approaching 32 years of age after 15 years at Willowbrook, has learned to travel each day to a workshop on his own, telephone that he has arrived, buy a meal on his own, make his own tea and cook eggs. He said recently that "being in Willowbrook was a living death."

Frederick Sutton said that his 54-year-old sister, in a group home since last April, now conversed and learned.

Last November, unhappy parents proposed that three top state officials be held in contempt for lagging in carrying out the 1975 agreement. But since then, the wrangling appears to have softened.

A stipulation is being worked on to present to Judge John R. Bartels in Federal District Court in Brooklyn March 10. One aspect would accelerate efforts to find community settings—residences for up to 15 retardates and supporting staff members or placement with families.

### Placement Goals Listed

Barbara Blum, the assistant state commissioner of mental hygiene supervising services for the retarded in the

metropolitan area, said the proposed new goal would be to place 50 residents a month up to Oct. 1, and 75 a month for the following six months and 100 a month for the ensuing year.

This would compare with only 28 placed last month. The state agency missed the original deadline for 200 placements in the year ended last March 31, moving only 131 into communities, Mrs. Blum said 224 had been relocated since.

Commissioner Blum said there had been problems of community opposition and difficulties with building codes. But she said that "in every instance, the setting is a better life situation for the individual." The court-appointed Willowbrook review panel said that the quality of placements had been "uniformly good."

The review panel, with Dr. Jennifer L. Howze as executive director, has made six-month reports on the overall court agreement through last December. These have decried "broken promises," charged deficiencies in staffing ratios and complained of delays in individual progress plans for all residents.

Dr. Cannon, who is 41 years old, became Willowbrook director last July, after earlier service there in 1968 when it had 5,600 residents, and in 1974, when complaints were at their height. Five other choices turned down the job first, he said.

"The people involved are good people to work with," he said, in explaining why he took the job. "And now we have money—no facility ever had adequate funding until this judgment.

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I'm committed to depopulate Willowbrook and move people into the least restrictive environment."

Dr. Cannon said that only "probably half" of the residents now had the programs he would like. These include 600 to 700 in school on the grounds or outside, 500 in workshops there and outside, and 93 in a model demonstration program started after the review panel's recommendation.

#### Daily Living Drills

In the model program in the two-story brick Building 23, residents are being drilled in "activities of daily living"—how to dress themselves and brush their teeth. Toilet training is a procedure of five to 15 steps.

One attendant worked with four young women—the ratio used to be one to nine—moving a ball along a wavy pipe to develop motion capability and also to concentrate attention. A girl stepped over low bars, learning to lift her feet and coordinate large muscles. Another matched colors of disks and bowls, and was rewarded with at least praise, sometimes with candy.

Ninety-three percent of the residents have some kind of program, Dr. Cannon said. But he reported only weak efforts for some groups so far—for instance, 400 blind retardates.

About a third of the residents are children, the youngest now about 7. Willowbrook admissions have been virtually frozen since an initial court order in April 1972.

Building 61 has 131 residents who take part in a workshop set up within the last year for nonacademic programs in line with court requirements. The residents are chosen by vocational rehabilitation counselors after training in recognizing colors, sizes, shapes, textures.

At one session, a woman carefully took metal nuts from a pile. She placed one nut in a circle, drawn on paper. She filled 10 circles—10 nuts, then transferred them to a box. When she had 10 boxes, she emptied the 100 nuts into a bag.

The workshop was carrying out a contract, and the residents were being paid piecework rates to give them at least the state minimum wage, \$2.30 an hour. Another project assembles pens—broken down into an eight-step process.

#### Own Television Set Bought

Building 32 houses the most successful residents. It has single-occupancy and double-occupancy rooms, with beds and armchairs. One young man has a television set of his own, bought with earnings from a Queens workshop to which he travels daily by Willowbrook bus. Proudly, he said that he and his visiting brother had painted the room.

The building has 115 residents, down from 250 a couple of years ago. Seventy-five work in vocational programs outside Willowbrook.

One major staff shortage is in physical and occupational therapy. In Building 15, one leader said every one of 75 women residents needed physical therapy. Four assistant trainees do what they can, following a physician's prescription.

Dr. Cannon said that the staff had stabilized. It used to have a turnover approximating 40 percent a year—110 percent in the direct-care staff in 1968. Now, Dr. Cannon said, young people have been attracted, both to help others and to gain valuable experience.

One element of the court stipulation being developed with help of Bruce J. Ennis, of the New York Civil Liberties Union and Mental Health Law Project calls for a state contract with United Cerebral Palsy of New York. The agency is to take over and administer five Willowbrook buildings for 250 to 300 residents with its special expertise.

Last August, Building 52, a former physician's residence, was turned over to the Association for Children with Retarded Mental Development to operate as a hostel for six residents. On Willowbrook's own grounds, it's a half-way house—like the residences Commissioner Blum must find outside.

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