

Big Day for Ex-Residents Of Center for the Retarded

By CELIA W. DUGGER

For decades, Willowbrook State School on Staten Island was a barren warehouse for more than 5,000 mentally retarded people, a place where children lay naked and untended on the floors of locked wards, where the air stank of urine and echoed with the moans and cries of residents.

Willie Mae Goodman's 4-year-old daughter was in Building 14. "She wasn't clean," Mrs. Goodman recalled this week. "You could smell her. Her little toes would be so chafed I had to pull them apart. I had to cut her hair

eral court supervision over former Willowbrook residents. Virtually all the surviving residents, most of them severely or profoundly retarded, now live in group homes, including Mrs. Goodman's daughter, Margaret.

Judge Bartels, the state and lawyers for the retarded also signed a document that permanently requires the state to keep the former Willowbrook residents in community homes.

The judge is 95 years old now and peers closely at legal papers to read them. The lawyers are

The former residents of Willowbrook, once neglected and brutalized, now cook and shop and marry the people they love. They gathered yesterday for one last, emotional time in Federal District Court in Brooklyn to celebrate what they had wrought.

While so many other social problems — homelessness, poverty, mental illness — have resisted solution, New York's reforms

Continued on Page B3, Column 1

A Permanent Requirement

The institution came to symbolize everything that was wrong with the care of the mentally retarded, prompting a lawsuit and extensive reform of the way the retarded were treated in the state.

This social transformation to care in small group homes reached a concluding milestone yesterday as Federal Judge John R. Bartels ended 18 years of Fed-



Ozier Muhammad/The New York Times

Maureen Torres, 33, a resident of Willowbrook State School two decades ago, now lives at a group home in East Harlem.

Page 1 of 3

Big Day for Ex-Willowbrook Residents

Continued From Page A1

in the care of the mentally retarded have provided a life of dignity for thousands of people once written off as incurable "mental defectives" and have provided a model for other states around the country, the speakers at the court hearing said.

"The people at Willowbrook were not dumped into shelters or left to fend for themselves on the street," said Robert Levy, a lawyer for the New York Civil Liberties Union, which filed the Willowbrook suit in 1972.

While the state faltered in creating group homes for the mentally ill released from hospitals — many of whom ended up homeless — it delivered for the mentally retarded.

The difference can largely be traced to the involvement of the Federal courts on behalf of the retarded and the clear, simple solution it enforced, said David J. Rothman, a historian who wrote "The Willowbrook Wars" (Harper & Row, 1984) with his

An 'Extraordinary' Effort

"The effort to move the most handicapped citizens out of institutions was extraordinary," he said. "And in the end it stands as a stunning example of what can be done in community treatment."

In 1965, there were 26,000 mentally retarded people in New York State living in institutions and only a handful in community residences. Today, 26,000 live in 4,746 community residences scattered across the state. Fewer than 5,000 remain in institutions.

But parents of mentally retarded children are quick to note that there is still much unfinished business remaining: there are 12,000 people on waiting lists for group homes in New York.

Willowbrook, a sprawling campus with dozens of buildings on hundreds of acres, is closed now and the buildings have become part of Staten Island Community College.

Beginning in the late 1940's, Willowbrook offered a mean, often desperate existence to thousands of mentally retarded people. By 1962, there were 6,200 people there, 2,000 more than its capacity. The complex was overcrowded and drastically understaffed. As many as 60 extremely disabled people were packed into one big locked room during the day, for years on end, with only a few attendants to supervise.

Neglect was endemic. There were not enough chairs, so residents lay on the floor or in cribs. And there were



Fred R. Conrad/The New York Times

Federal Judge John R. Bartels, who yesterday ended 18 years supervising former residents of Willowbrook State School. Of the survivors, most severely or profoundly retarded, most now live in group homes.

not enough clothes, so they often wore rags or nothing at all.

Many could not feed themselves, and the shortage of workers meant residents often did not eat properly. The lack of supervision also allowed unchecked violence among the bored, despairing residents.

John Emro frequently visited his stepson, Scott, who could not walk, talk or feed himself. Mr. Emro remembers a room filled with young, lonely retarded people desperate for affection. "They'd hug you so tight it scared people," he said. "It was hard to get rid of them."

Shocking Images

Over the years there were brief flurries of attention. In 1965, Robert F. Kennedy made a surprise visit and denounced Willowbrook as "a snake-pit" where children lived in filth. Still, nothing much changed.

And in 1971 the State Legislature slashed funds for Willowbrook, further cutting its already inadequate staff.

The deepening crisis radicalized some of the doctors and parents. They went public for the first time.

Court supervision ends over those who left a center for the retarded.

They picketed the administration building, blocked traffic on the street and talked to reporters.

But it was a television report by Geraldo Rivera on ABC News, on Jan. 6, 1972, that catapulted Willowbrook into the national consciousness.

An outspoken doctor dismissed from his position at Willowbrook smuggled the reporter into one of the wards. A handheld camera captured shocking images: naked children on the floor, walls smeared with feces, a room virtually barren of furniture.

Two months later, the New York Civil Liberties Union sued the state on behalf of the New York State Association for Retarded Children in Federal court. In 1975, soon after Hugh L.



Ozier Muhammad/The New York Times

"You could smell her," said Willie Mae Goodman, left, describing her daughter, Margaret, as a 4-year-old resident of Willowbrook. "Her little toes would

be so chaffed I had to pull them apart. I had to cut her hair short it was so matted." Margaret, now 37 lives in a state-financed group home in Manhattan.

Carey became Governor, the state signed a consent decree with the plaintiffs, starting the single largest effort at deinstitutionalizing of the retarded in the nation.

It was a fortuitous meeting of the minds between the civil-liberties lawyers and the new Governor. Peter C. Goldmark, now president of the Rockefeller Foundation, was then Mr. Carey's budget director and negotiated the deal.

He had handled a similar case when he was Secretary of Human Services in Massachusetts. He was a believer in group homes. So instead of pouring millions into improving Willowbrook, building "a shinier prison," as Mr. Goldmark put it, he and the plaintiffs decided Willowbrook should cease to exist.

Over the last 18 years, two Federal judges, Orrin Judd and, after his death in 1976, Mr. Bartels, issued more than 50 orders and opinions and held more than 100 hearings as they prodded a sometimes balky state to follow through on the promise of community-based care for the mentally retarded.

In 1987, Willowbrook itself was closed, but many of its residents still remained in institutions. It was not until the end of 1992 that all but about 150 of the former Willowbrook residents had been moved to group homes, leading to yesterday's closing ceremony.

Crystal-Clear Message

At the hearing, state officials, lawyers and advocates for the retarded offered the soaring oratory of principles established and rights gained. But it was the people who lived the horrors of Willowbrook who brought the day down to earth. Their voices were garbled and distorted by their disabilities, but their meaning was crystal-clear.

Gary Cohen, 46, hobbled to the podium. A diminutive man born with spina bifida, he was placed in Willowbrook when he was 3 years old and lived there 24 years. Since he has left the institution, he said, he has learned to clothe himself and to add and to read.

He read haltingly from a statement he had written, and he did not flinch from the memory of Willowbrook:

"There was feces all over the place. It was the worst place I ever been in."

'A Long Way'

Robert Cantor rolled to the podium in a wheelchair, his arm curled in a permanent arc. "I'm married now," he said. "I've come a long way from Willowbrook. Thank you, commissioner of human whatever you call it." That got a big laugh from the audience.

A bit later, the 95-year-old judge had the last word. He sat alone on the bench in his black robes, a vast wall of white marble behind him. He spoke with a certain solemnity and sense of moment as he held his speech close to his eyes.

He paid homage to the parents whose love and work "on the outside brought progress on the inside." He recalled the state's resistance to some of his orders.

And finally, the Republican judge, first appointed to a state court by Gov. Thomas E. Dewey, concluded with a sentence that echoed Selma and Montgomery: "The retarded have really overcome and social justice has prevailed."