

# Decree changed view of care for retarded

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In April 1972, 5,343 mentally retarded persons were living at Willowbrook State School under conditions so intolerable that the New York Civil Liberties Union filed suit to get them out.

The plaintiffs represented people like Lara Schnepps, a severely retarded 4-year-old who — according to the lawsuit — almost died because of inadequate medical care; 10-year-old Nina Galen, who was given tranquilizers instead of toys; and Evelyn Cruz, 13, who lived on a ward with 100 other children staffed by only four attendants.

There was little doubt that Willowbrook (since renamed the Staten Island Developmental Center) was a terrible place to live — “It was so bad it was off the end of the spectrum,” as one person put it — but the validity of the lawsuit was questioned by many.

Willowbrook was not a prison, but an institution; its residents were not forced to live there. If the parents and the NYCLU didn't like the conditions there, the residents could go home. The situation was maddening, but was it a violation of civil rights?

The NYCLU wanted the state to close Willowbrook and put its residents in group homes, but plenty of people thought that was stretching the United States Constitution too far.

There were indications that even Judge Orrin Judd of the U.S. District Court in Brooklyn had his doubts. Yet on April 30, 1975 — 10 years ago this Tuesday — Judge Judd signed the Willowbrook Consent Decree, a landmark document which settled the lawsuit and marked a new beginning in New York

State's concept of care for the mentally retarded.

Most of the 29-page consent decree outlined standards of care for Willowbrook residents. But the real bombshell, although only vaguely outlined in the document, was an agreement that Willowbrook would reduce its population to 250 by 1981 and transfer all the remaining clients into community residences.

Moreover, the state indicated that the deinstitutionalization would not be limited to Willowbrook, although those clients covered by the lawsuit would get first priority. Through the consent decree, the state government essentially agreed to at least partially dismantle its institutional system for the retarded and establish community-based services.

The implications were staggering — not only for Willowbrook residents, but for all mentally retarded persons in New York State and even extended by implication to the rest of the country. It was the first time New York State acknowledged that retarded persons do not belong in institutions; that retardation is not a disease requiring lifelong isolation from the rest of society, but a condition which can permit a happy and productive life in the mainstream community; that the state had a responsibility to provide the services which would allow the retarded to live in the “least restrictive setting” possible.

Certainly, the transfer of clients from the institution to the community is what made the Willowbrook case a landmark. While it was not the first class-action lawsuit against an institution for the retarded, it was among the first that went beyond demands that an institution be merely upgraded.

“It (the Willowbrook Consent Decree) was the single most important action which brought change in the field of mental retardation,” says Arthur Webb, commissioner of the state Office of Mental Retardation and Developmental Disabilities (OMRDD). “Its magnitude in terms of effect on social policy was unprecedented.”

In fact, the year the consent decree was signed, New York State supported less than 6,200 retarded persons in the community (the majority in family care, which resembles foster care), while more than 20,000 resided in institutions. Today, the institutions house fewer than 11,000 — and the number is still declining — while more than 18,000 are living in community residences financed by the state.

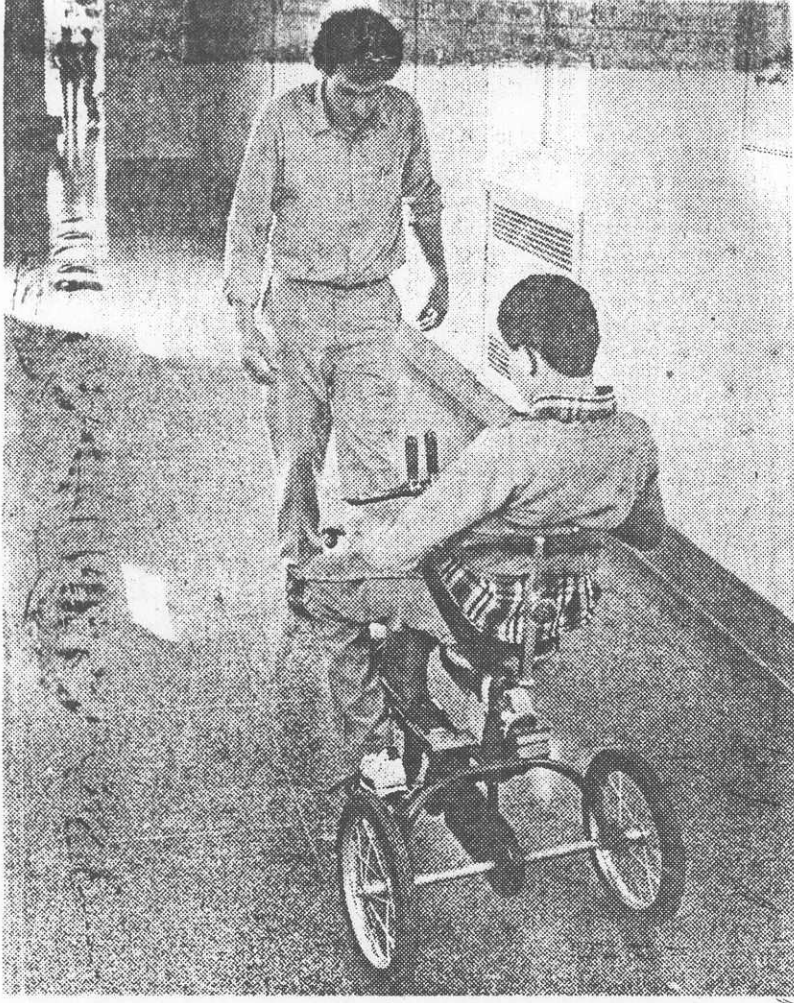
Not surprisingly, the exodus out of the institutions has been led by clients at Staten Island Developmental Center (SIDC), although the original timetables set down in the consent decree proved to be wildly optimistic. By 1981, when the institution was supposed to have only 250 residents, there were still almost 1,500 living in the facility; community placement proved to be much more difficult than anyone had imagined.

There are still about 600 clients at SIDC. Of those who have left, about 1,100 are now living in

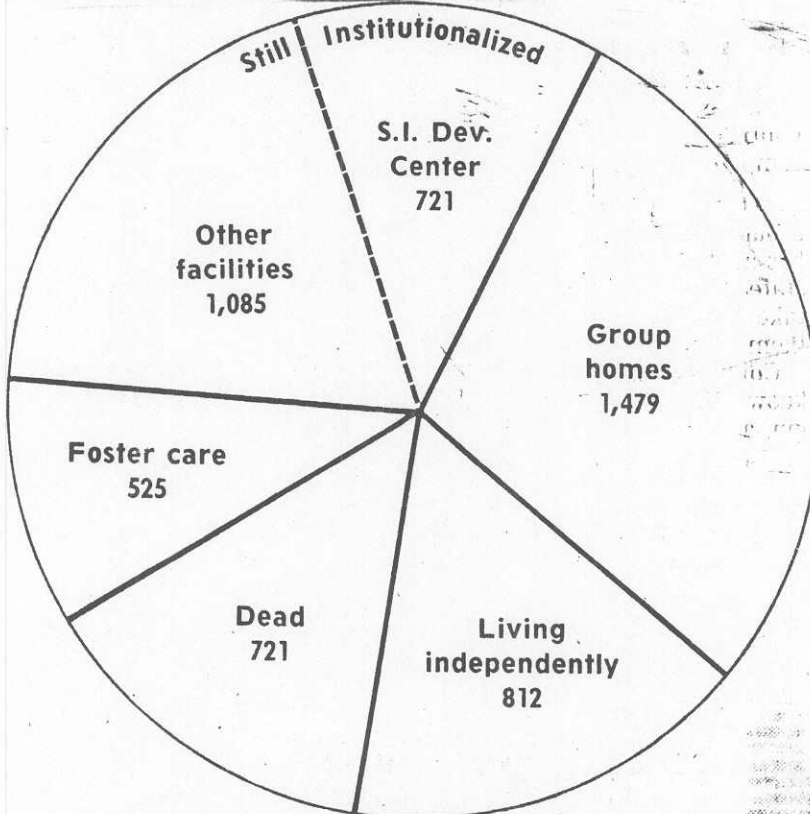
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A Staten Island Developmental Center client sits in a wheelchair in a hallway.

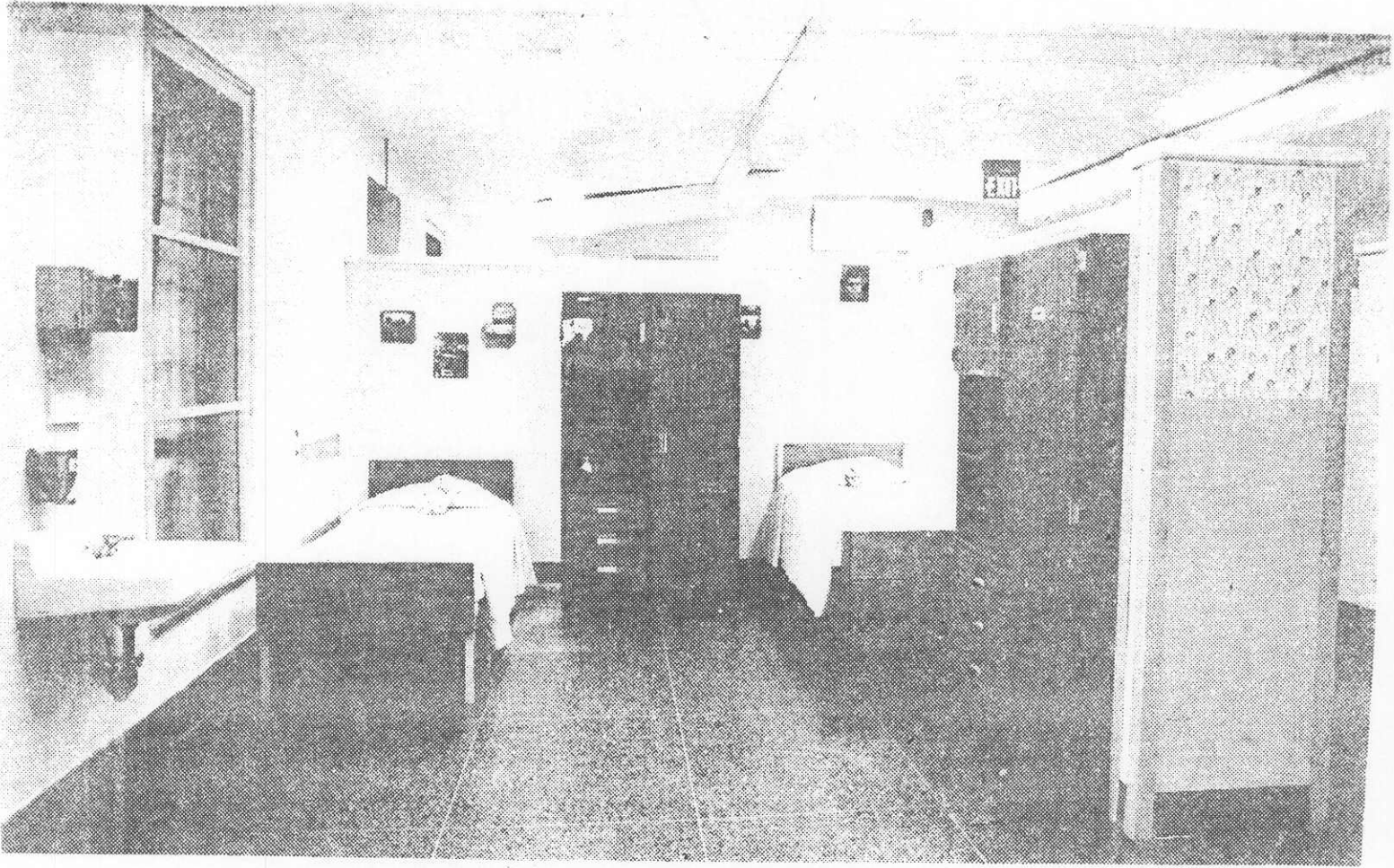


Steve Daurio, a psychologist, works with a client on a modified tricycle in a hallway.



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There were 5,343 residents of Willowbrook State School in March of 1972. This chart shows what has happened to them as of Dec. 31, 1984. S.I. Advance Graphic by James Warren



Large wards, which formerly had dozens of beds side by side, are now divided by partitions to separate sleeping areas into mini bedrooms.

other developmental centers around the state and are awaiting placement in community residences. A good share of former SIDC residents — more than 2,800 — are already living in the community: Some returned to their families; others were placed in group homes, supervised apartments or "family care," which resembles foster care: a few, who it turned out never belonged in Willowbrook in the first place, are now living independently.

The state continues to move residents out of SIDC at a rapid pace — the institution should reach the 250 level by next April. It is scheduled to close in 1987, a decision inspired by the state's eagerness to close the book on Willowbrook. Webb says it proves the state is willing not only to abide by the consent decree, but to go beyond it.

"I think we've more than met the intent of the consent decree," he says.

Others debate that point —

they are upset about the state's attempts to amend the consent judgment so that "community residences" include facilities with as many as 50 beds. Presently, Willowbrook residents must be put into group homes with no more than 15 beds. Rob Levy, an NYCLU attorney, terms the state's proposal "a perversion of the idea of community placement."

Moreover, lawyers at the NYCLU and other advocates for the Willowbrook residents claim the quality of care at SIDC is still deficient and that the state should be placing residents into the community at a faster pace.

But despite the still-raging battles over implementation of the consent judgment, there is a general acknowledgement that the settlement marked a turning point in the state's care of its mentally retarded citizens.

"Without the consent decree, we would still be jerking around, acting like a big institutional system," Webb says.

"It's given the state some

goals; it's established standards," Levy said.

"That's the greatest success of the consent decree," says Chris Hansen, an NYCLU attorney who worked on the Willowbrook case from 1973 to 1983. "In 1972, the idea of community placement was a radical idea — we were the lone voices in the wilderness. I remember in 1975, there were parents who said 'over my dead body' would their children be taken from the institution and be placed in the community.

"The real triumph of Willowbrook is that it changed the view of how we should care for the mentally retarded. Today, we get guys like Jim Walsh (director of SIDC) talking about community placement, and I think that's terrific."

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