

A look back

Willowbrook case continues

By JULIE MACK

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In 1975, state officials and advocates for the retarded, in reaching a court settlement, figured it would take 13 months to implement reforms at Willowbrook State School and six years to reduce the institution's patient population from 5,300 to 250.

Today, a decade after those promises were made, the institution — now called the Staten Island Developmental Center — still has more than 600 clients and, according to some, its quality of care is still amiss. Yet the state commissioner in charge of services for the mentally retarded says the landmark document which forced the reforms is "outdated" and should be abolished.

The document, the Willowbrook Consent Decree, was signed by Gov. Hugh Carey to settle a class-action lawsuit charging the state with neglect of Willowbrook residents. The lawsuit was filed in 1971 after parent protests and media investigations revealed the institution's squalid conditions.

The 29-page consent judgment established minimum standards for every aspect of client care at the institution. The document also specified that the state eventually place all but 250 of

SIDC's residents into community residences.

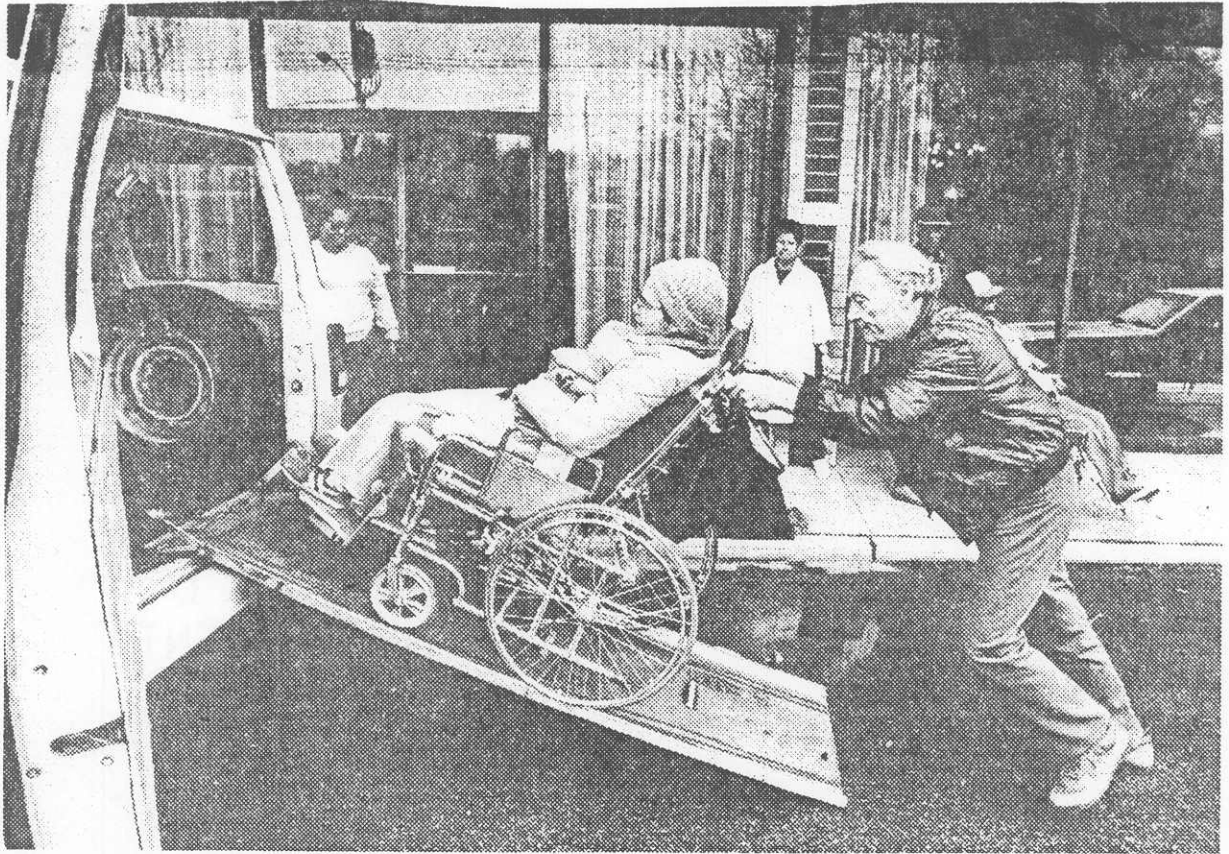
The consent judgment was a victory for the Willowbrook residents, who were represented in

the case by the New York Civil Liberties Union. But it has proved to be a qualified victory, according to the NYCLU. "We've transformed the rhetoric, but we

haven't gone as far as we would like in transforming the reality," said Chris Hansen, an NYCLU (See DECREE, Page A 12)

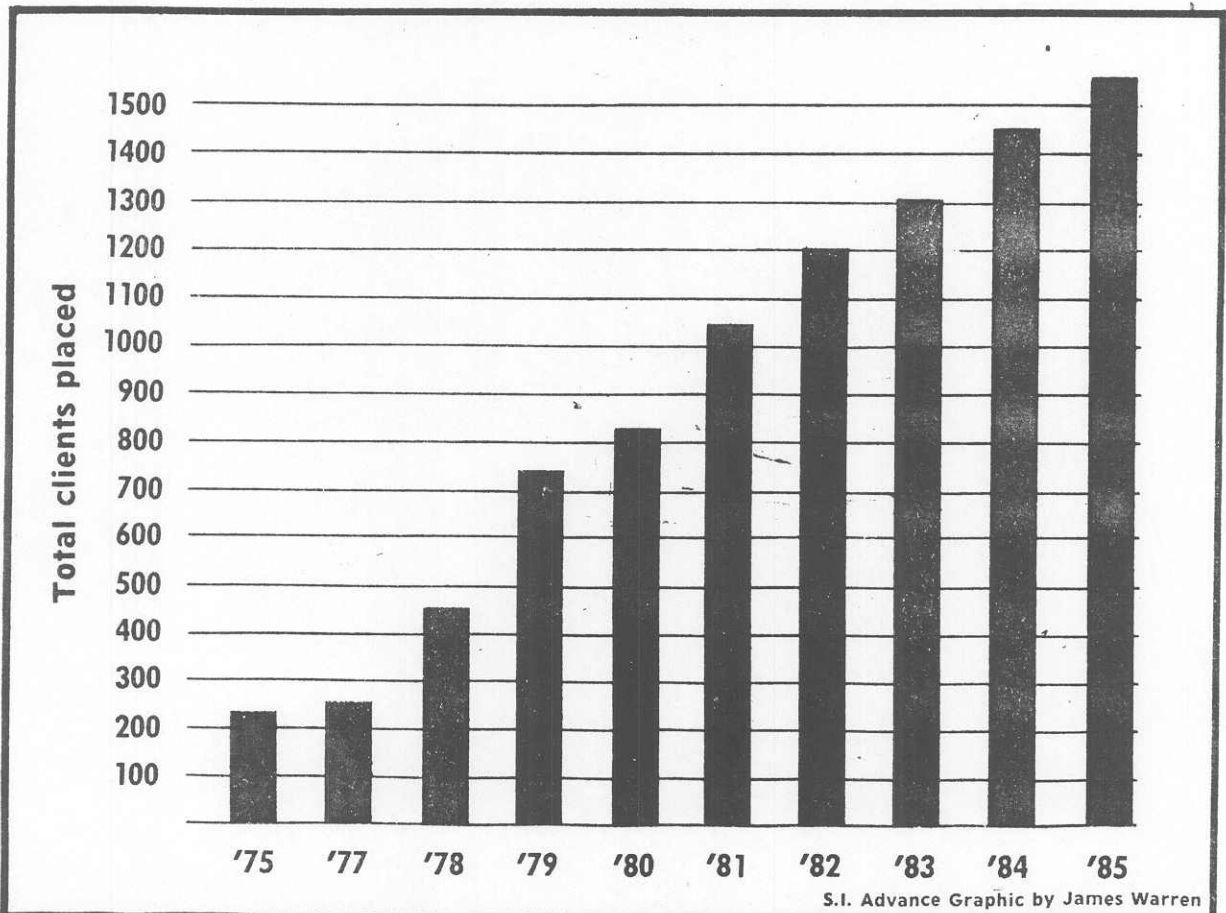


Clients work at the United Cerebral Palsy-New York City Vocational Rehabilitation Center, New Brighton.



Doug Desderdick is pushed in his wheelchair into a UCP van at the Fountains apartments on his way to a daily work program at the vocational rehabilitation center in New Brighton.

S.I. Advance Photo by Tony Dugal



Figures show community placement of Willowbrook clients starting in September, 1975. Subsequent totals are as of March for each year.

attorney who worked on the Willowbrook case from 1973 to 1983.

Indeed, a decade after the class-action suit was supposedly settled, the Willowbrook case continues. Negotiations go on. Both the NYCLU and state attorneys still periodically troop to U.S. District Court for still another hearing. Even now, the plaintiffs and defendants are awaiting yet another court ruling.

The issue since 1975 has been implementation. When the consent decree was signed, the state said it would take 13 months to upgrade Willowbrook. The state also said it would reduce the institution's population to 250 by 1981.

The SIDC still has more than 600 residents, and almost half of those who left are living in other institutions around the state. Arthur Webb, commissioner of the state Office of Mental Retardation and Developmental Disabilities (OMRDD), says all current and former Willowbrook residents eventually will be resettled in the community, but it will take another 10 years.

But as far as the quality-of-care issue, Hansen said the institution is still deficient. "My view is that except for the fact that Willowbrook is less crowded, I don't think the clients are really any better off than they were in 1972," Hansen added.

Both the state and NYCLU acknowledge that, in retrospect, the original timetables outlined in the consent decree were unrealistic. "We were naive," Webb says.

In Hansen's estimation, the primary problems have been "a lack of commitment and a lack of competence." He argues that has OMRDD has not been aggressive or innovative enough in establishing group homes.

Webb disagrees, and claims most of the problems have been outside of the control of his agency. "To this day, I don't think the ACLU understands the complexity of budgeting and policy," Webb says.

He said one of the biggest problems in community placement has been public opposition to group homes. "We get a lot of resistance," Webb said, noting that the state must seek approval of the local community board for every group home. "Community boards have gotten very, very smart in knowing how to delay a project."

Webb's agency must also contend with New York City's housing shortage. Not only does the current market make it difficult to find suitable sites, but it also means sellers are less willing to do business with the state.

"So many state agencies are involved in the purchase of property for a group home and it can take months, even years, to get everything straightened out," said Rita Martin, who until recently worked for OMRDD in group home placement. "Sellers are not going to wait that long. The state loses out on a lot of possible sites that way."

Because of these issues, "for every five or six sites we pursue, we may only end up with one," Webb said.

The NYCLU lawyers acknowledge that community placement has been a difficult challenge, but "the problems are the state's own making," said Rob Levy, the NYCLU attorney currently assigned to the case. "Certainly, there is a housing crisis, but the state's method of looking hasn't been that efficient. The state hasn't been as creative as it can be."

The rate of community placement is not the only issue still hanging over implementation of the consent decree. An even more serious battle has shaped up over the size of the community residences: The consent decree limits the group homes to 15 beds for mildly and moderately retarded people and to 10 beds for the severely and profoundly retarded; the state wants that amended so it can build "community" facilities with as many as 50 beds. The state's proposal is currently before Judge John Bartels of the U.S. District Court in Brooklyn.

Levy calls the state's plan "a perversion of the idea of community placement." But Webb says the larger facilities are necessary to care for people who have multiple disabilities and need constant medical attention. He adds that his agency plans to build "only four or five homes over 20 beds in the whole state."

"Having too many people in a setting is definitely not home-like," Webb said, "but we have some clients who are severely handicapped, and for them smallness of the residence is not a critical issue. It is more important that they receive a higher level of intensive services which you can only get in a bigger setting."

Yet Levy and others say studies have shown that a small setting benefits even the most severely handicapped people. Ray Gannon, of the Consumer Advisory Board, an independent state agency that serves as an advocate for current and former Willowbrook patients, says the severely handicapped more than others need the kind of individualized training and attention available only in a small group home.

Because of issues like this, Webb would like the courts to put the consent decree aside.

"I will have felt I would have accomplished something if we could negotiate our way out of the consent decree," Webb said. "The policies of the decree are now embedded in state policy. The time is now for a substantial rearrangement."

But such a rearrangement does not seem likely, if the NYCLU has anything to say about it. "They keep talking about wanting to regain control of their system, but I don't think there's a need for us to go away," Levy said.

"When you realize how hard it is to achieve really fundamental social reform, the consent decree has been an amazing success. But its implementation has gotten bogged down and that's a major disappointment."

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