

\$100 million spent to improve Willowbrook

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A series of federal court orders directing a reversal of "inhumane and shocking" conditions at Willowbrook State School has cost state taxpayers in excess of \$100 million, an Advance study of state records reveals.

Approximately three-quarters of the court-related costs have gone to improve care for 5,241 mentally retarded persons then living at Willowbrook, the study indicates. Much of the remainder has been spent on administration and setup of an intricate maze of agencies charged with overseeing the institution's workings or implementing the terms of the so-called Willowbrook Consent Judgment of 1975.

The complex system today consists of a state Office of Mental Retardation and Developmental Disabilities, a state Metropolitan Placement Unit, a state Borough Developmental Services Office, a Willowbrook Review Panel, a Technical Assistance Unit, a Professional Advisory Board, a Consumer Advisory Board, and perhaps a dozen additional advisory boards, units and panels on the grounds of the 382-acre campus.

Not one of those agencies existed three years ago.

In addition to the \$100 million spent because of the court orders, since 1975 New York State has allocated approximately \$160 million for the budget of Willowbrook, now called the Staten Island Developmental Center. Federal aid to the institution for special projects, some of them court related, has totaled about \$50 million since the signing of the decree.

"I can't argue with your figures,"

Mental Retardation Commissioner Thomas A. Coughlin said when told of the court-related costs. "We knew it was going to be expensive because to go back and undo all that was wrong at Willowbrook for 25 years — to change a system in place that long — is costly indeed."

The state comptroller's office has not attempted a comprehensive financial audit of the Island institution since 1973, spokesman Ronald Tarwater said. Nevertheless, Coughlin maintained that only a "negligible percentage" of the funds has been lost through waste, theft or inefficiency, as in "any large organization," he said.

Parent groups representing the mentally retarded residents sued the state in 1972 to stop abuse and neglect at Willowbrook, where people languished on overcrowded, filthy ward floors.

In 1975, without admission of guilt, Gov. Carey and top aides consented to sweeping changes at Willowbrook that eventually will leave their mark on all publicly run institutions. Steps to which Gov. Carey agreed included improved staffing levels, new programs, an end to human experimentation and, essentially, a new, humanitarian approach to the treatment of the retarded.

At the heart of the order was a state promise to dismantle the giant developmental center by 1981 by transferring all but 250 native Staten Islanders to small, community facilities where the retarded are deemed capable of more growth.

Approximately 2,200 residents remain at Willowbrook today, about 580 of whom are under the care of the United Cerebral Palsy Association of New York State. Former Willowbrook residents

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have been dispersed to other institutions and a variety of community settings established since the court order. All have been entitled to relief from the judgment.

Since the signing of the court order, according to the best available estimates, New York State, with the help of Medicaid funds, has spent:

¶ Approximately \$50 million to upgrade programs and staffing at Willowbrook itself. In addition, perhaps \$20 million has gone to improve 12 Willowbrook-related facilities, where many of the residents have been transferred.

¶ Approximately \$10 million for community placement of Willowbrook residents, including so-called purchase-of-service funding paid by the state to not-for-profit groups in return for the operation of community group homes, day programs and the like.

¶ Approximately \$9 million for capital improvements and planned improvements at Willowbrook, which once lacked basic safety devices including smoke alarms, sprinkler systems and proper entrance and exit requirements in many of its residential buildings. Some of these investments, however, were not court-related.

¶ Approximately \$5 million has been used to set up a series of panels and units as called for under the court decree. The Willowbrook Review Panel, for one, charged with monitoring monitoring the monitoring agencies as well as the care for the mentally retarded and then reporting its findings to the court, has a yearly budget of \$300,000.

¶ An undetermined amount of state funds for other purposes, such as payments to public and private attorneys who represent the state in on-going court disputes.

Just recently, the federal judge in Brooklyn in charge of the Willowbrook case, John R. Bartels, said that the state must pay "reasonable fees" to attorneys who have represented the retarded residents since 1972. Attorneys for civil-rights firms are seeking more than \$1 million.

In addition, the Carey administration has pledged to extend the benefits of the Willowbrook Consent Judgment to 15,000 mentally retarded persons residing in other institutions throughout the state. New York is the only state in the nation to adopt such a sweeping program.

The Advance study, attempted by a team of reporters in the past month, in-

involved a review of financial records at Willowbrook and in Albany. The reporters encountered an accounting system at Willowbrook described by one budget official as "screwed up — that's the best way to put it."

The budget official, as well as Coughlin and state aides in Albany, suggested that the institution's accounting mechanisms, now manual, would be more "finely tuned" when the entire state system is put on a central computer system this year.

Coughlin maintained that some court-ordered costs could have been avoided "but the judge didn't agree with me." He referred to the state's recent dispute with the parents over further staffing of a consumer advisory board. The state argued against it on the ground that it was a "duplication of effort" but the review panel disagreed and prevailed.

"I don't care if we're spending money to provide direct care to residents," Coughlin said. "But when we have to put another hundred thousand in to provide another monitoring agency, it gets ridiculous."

Coughlin also conceded that the state Office of Mental Retardation and Developmental Disabilities, which last month replaced the retardation division of the Department of Mental Hygiene, has not kept track of just how much the Willowbrook Consent Judgment has cost.

Asked if the expense conceivably could be more than \$100 million, Coughlin, a director at Willowbrook in 1976, confided: "It could be...It's going to cost even more for five or six years. When we put our name on that document, we backed it up with money."

Former Gov. Malcolm Wilson, when presented with a similar document in 1975, refused to commit New York State to the radical change — and the cost — the court order implied.

But Carey promised to do so in his campaign for governor.

"It was not a very nice place to live before," Coughlin said, referring to the pre-court order days of Willowbrook. "It had to stop...Now, even though people still beat on it, New York City has one of the best systems (for the retarded) in the world."

And while most agree that the Willowbrook of today is a drastically improved institution over what it was three years ago, parents and Willowbrook Review Panel members continue to criticize institutional care for the mentally retarded. Some say Willowbrook's lingering woes are inherent to institutions worldwide. They argue that only when the developmental center is expunged — or at least scaled down markedly — will the court orders have achieved their purpose.

State officials, too, struggle with the irony of funding a system that is being dismantled. "But you have to start somewhere," Coughlin said. "And nobody ever said it would be easy or cheap."

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