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Willowbrook 'Revolution' Recalled

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Albany — On April 30, 1975, shocked by images of twisted bodies in squalid rooms, Gov. Hugh L. Carey signed a court order that would revolutionize care of the mentally retarded in New York.

Yesterday, on the 10th anniversary of the Willowbrook consent decree, Carey and some of the people he hired to shape and implement that historic change gathered to remember the experience and reflect on its lessons.

"The plaintiffs, the defendants, all became advocates," Carey said at a panel discussion convened by the Rockefeller Institute of Government and the State Office of Mental Retardation and Developmental Disabilities. "Because of that advocacy, New York now experiences a better day."

Willowbrook State School was a name that became synonymous nationwide with neglect and abuse of the retarded after widespread reports about overcrowding, filth and neglect of patients there. It had 5,400 residents when a group of parents and American Civil Liberties Union lawyers took the state to court in 1972.

Today, 2,887 of those members of the Willowbrook suit live in the community. Only 434 of them are left at the Staten Island institution, which Gov. Mario Cuomo has promised to shut down by 1987.

"Your vision is not only intact today, it is still the guiding light," Ilene Margolin, the governor's deputy secretary for human services, told the panel members — Carey and four of his former top aides. "The vision and the leadership of this group is really what continues to guide us."

The policy change set forth in the consent decree and championed by the Carey administration began removing the retarded from state institutions, reducing their numbers in institutions from 20,000 to 10,700 today, with 15,000 in group homes.

Carey praised his former staff members, noting particularly the feistiness that made him appoint Thomas A. Coughlin III as the first head of the office of mental retardation. "Tom is the kind of fellow who will give you backtalk. He doesn't flinch," Carey said.



Panelists Hugh Carey, left, Thomas Coughlin and Richard Bartlett discuss effects of lawsuit
Newsday/Dick Kraus

Coughlin, who now heads the state prison system, remembered the distrust and antagonism that marked the relationship between the court-appointed Willowbrook Review Panel and the state. "They felt the only way to make the system work was to tear it down and build another," Coughlin said.

But out of that antagonism came dramatic change that most of the officials yesterday said could not have happened without the court. Arthur Webb, the present commissioner of the mental retardation agency, cited the "pivotal importance of advocacy and civil rights groups in this country; without them, we wouldn't be where we are today."

Barbara Blum, who headed the unit that found community placements for the Willowbrook cli-

ents, recalled the anger and ignorance that faced officials whenever they attempted to open a group home in the community. That antagonism, she said, has lessened in the last decade. And Carey remembered his own amazement at finding liberal Democrats in his Park Slope, Brooklyn, neighborhood demonstrating against a home. "It was so-called vaunted intellectuals saying these people didn't fit into our block," Carey said.

"We don't have to fight policy every day now," Webb said. "We have to fight pace, a little bit of budget, but we don't have to fight policy."

Carey said he visited a group home last week in Brooklyn, and recognized some of the faces from a decade ago. "I had seen them in Willowbrook. And now I saw them in Brooklyn. These people who were beyond help are now helping themselves."